Reaching out to carers of an individual with schizophrenia and a psychosis disorder: A framework for the construction and evaluation of a web-based intervention to improve carer wellbeing and quality of life.

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Reaching out to carers of an individual with schizophrenia and a psychosis disorder: A framework for the construction and evaluation of a web-based intervention to improve carer wellbeing and quality of life.

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Abstract

Less than one percent of the population has been estimated to have been diagnosed with a severe mental illness (SMI), of which 80%-86% are will require ongoing need for support. Recent figures show that one in ten people has a caring role, with such roles being shown to have a negative impact on carer health.

The growth and popularity of the internet (or world wide web) suggests that this could be a useful medium for support provision, and this has been reflected in recent policy. Previous literature has outlined the valuable contribution carers have in caring for their ill relative and the negative impact this can have on carer health. The use of web-based resources can further promote carer empowerment, increase access to support for their emotional wellbeing and to assist in the management of the caring role. The research informing this thesis aimed to explore factors which constitute effective web-based support for carers of individuals with an SMI.

Eight carers and six mental health professionals participated in the research study, which adopted a mixed-method approach within a conceptual framework informed by a critical realist stance. Data was collected using qualitative comparative analysis of health-focused questionnaires and research diaries, and thematic analysis of qualitative interviews.

Analysis resulted in five key themes: 1.) Expertise via experience 2.) Empowerment through knowledge 3.) Connection, understanding and advice online 4.) Personal preference: considering the accessibility of the internet, and 5.) The landscape of carer support. Further analysis included the identification of generative mechanisms and contexts influencing the use of and impact of web-based resource usage on carer wellbeing and quality of life.

This thesis presents the process and findings of the research study, culminating in the suggestion and presentation of a framework designed to be of utility in the construction and evaluation of web-based needs-aligned intervention/support for carers of individuals with SMI. The framework is aligned to the key themes emerging from data analysis.

Potential directions for further research and development within the area of web-based provision for carers and family members are summarised.

Contents

Table and Figures

Glossary

Abbreviation	Full Term
AC_QoL scale	Adult carer quality of life scale
Apps	(Smartphone) Applications
CBT	Cognitive behavioural therapy
CMO configurations	Context-mechanism-outcome configurations
CNAF	Carer needs-aligned framework
csp-set QCA	Crisp-set QCA
DCMS	Department for Digital, Culture, Media and Sport
DHSC	Department of Health and Social Care
DoH	Department of Health
DPS	Dynamic patterns synthesis
DSM-V	Diagnostic and statistical manual of mental disorders (5th edition)
EE	Expressed emotion
FEP	First episode psychosis
fs-set QCA	Fuzzy-set QCA
GIF	Graphic interchange format
GP	General practitioner
HADS	Hospital anxiety and depression scale
HCI	Human computer interaction
HOC	House of Commons
IAPT	Improving access to psychological therapies
ICD-10 **ICD-11**	International classification of diseases (10th or 11th edition)
Mpbs	Megabits per seconds (measure of internet speed)
MH FYFV	Five year forward view for mental health
MOST model	Moderated online social therapy model
NHS	National health service
NICE	National institute for clinical excellence
NPT	Normalisation process theory

Abbreviation	Full Term
NTW	Northumberland, Tyne and Wear
QCA	Qualitative comparative analysis
QoL	Quality of life
RCT	Randomised control trials
SMI	Severe mental illness
UK	United Kingdom
WEMWBS	Warwick-Edinburgh wellbeing scale

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee / University Ethics Committee on 26th October 2016.

I declare that the Word Count of this Thesis is 76,652 words

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Date: 29.09.19

Chapter 1. Introduction

In the United Kingdom (UK) today, it is estimated that one in six adults are diagnosed with a common mental problem/disorder (McManus et al, 2016). Diagnosis of severe mental illness (SMI) is less common, with 0.7% of the population estimated to have a diagnosis of psychotic disorder such as schizophrenia (Bebbington et al, 2016).

The National Institute of Clinical Excellence (NICE) (2014) suggest that 14%-20% of individuals diagnosed with schizophrenia will make a full recovery from an initial episode, without further relapse. This indicates that 80%-86% of individuals diagnosed as such will present ongoing need for support and intervention. This further suggests that, for many of these individuals, part of this ongoing need for support will involve family members in the role of carers. The 2011 UK census estimated that one in ten people in the UK have some form of caring role. Comparing the amount of unpaid care in England and Wales between 2001 and 2011, The Office for National Statistics (2013) indicated that these figures are rising. The Carers Trust (no date) further estimate that one in four individuals have a caring role relating to an individual with mental health issues. The potential negative effects of such caring roles and the associated need for support for carers is well documented (Fortune, Smith and Garvey, 2005; Marsh, 1994).

Since its initial inception and creation, the world wide web, or internet, has grown exponentially in terms of general popularity and utilisation. For example, the Office for National Statistics (2018) report that 90% of UK households have access to the internet, with 86% of adults engaging on a daily basis. These figures are likely to go on increasing, as the use of digital technologies, including the internet, become increasingly embedded as part of the daily lives of what Bennet, Maton and Kevin (2008) term ‘digital natives’ (individuals, and indeed whole generations, who have grown up and subsequently aged with digital technologies representing a central component of their lives).

Given the identified needs of carers in terms of support, and the existence and popularity of the internet, a variety of support formats and sources have emerged over time to address and augment the support and information needs for carers. For example, Carers UK (no date) give information regarding how internet-based resources can be of help, and indeed list several such resources for carers to access including their own online forum. However, given the nature of the internet as an open forum in terms of access and provision of material, there are potential issues in terms of accuracy and quality of information, which

in some cases may be counterproductive and problematic (Eysenbach and Jadad, 2001; Berry, Bucci and Lobban, 2017).

This thesis draws upon the findings of a research study which explored the experiences and perceptions of carers of individuals with severe mental illness regarding their use of web-based support. The intent of the thesis is to draw upon these experiences to inform a framework of guidance for the evaluation or construction and provision of web-based support for carers of people with SMI.

This introductory chapter serves to provide a brief context for the thesis and the research study which informs it. Key issues relating to the role of carers for those with SMI are first summarised, including the importance of the definition of the caring role. The position and functions of web-based resources are then briefly summarised. The aims and questions of the research informing this thesis are then summarised, together with a brief outline of the research approach taken. Finally, the chapter ends with an overview of the structure of this thesis.

1.1: The role of the 'carer' in the UK: context of mental health provision

The prevalence figures highlighted in the opening section above underline the fact that carers have a central role in the ongoing support of individuals with SMI. The inherent potential negative effects of this caring role upon carers include isolation, increased hopelessness, fear, reduced Quality of Life (QoL) and wellbeing (Onwumere et al., 2016b; Wainwright et al., 2015, Hayes et al., 2015; Sin, 2013).

The importance of the caring role has been increasingly recognised in literature, and in government health policy. For instance, The Five-Year Forward View to Mental Health (MH FYFV) highlighted the valuable role completed by carers and argued for collaboration with these individuals to develop services (The Mental Health Taskforce, 2016). More recently, the Department of Health and Social Care (DHSC, 2018a; 2018b) proposed actions towards supporting carers. These included improving formal support in the caring role and the development of research projects to further understand carer supportive needs. However, there remains little consideration towards the supportive needs of carers within the NHS Long Term Plan (NHS, 2019).

This thesis argues that providing support to carers of individuals with an SMI can impact on the health of the carer and those they provide care for; the care recipient. A suitable metaphor being the safety instructions issued whilst travelling via an airliner. These instructions specify that parents must secure their own oxygen equipment before aiding children, despite the natural reaction to prioritise the latter. Thus, parents prioritising personal safety enables them to then ensure their child's safety. Using the above analogy, the provision of support to carers can not only increase their emotional health, but also enable provision of care and impact care recipient wellbeing. The literature chapter will provide a detailed outline regarding the influence of expressed emotion (EE) and proposed theoretical models of the relationship between carer and care recipient health (Lobban and Barrowclough, 2016; Kuipers et al., 2006).

It is useful at this point of this thesis to define the term 'carer', due to ongoing issues. For instance, some individuals have disputed the terminology or the assumption this applies to specific familial roles (Knowles et al., 2016; Sin, 2013). Additional complications arise in determining when an individual becomes a carer. Schulz and Quittner (1998) suggested that a carer is an individual who provides extraordinary care considered to be outside the socially-accepted realms of care, such as assisting an adult to dress. The definition of carer used within the context of this thesis is an individual "who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction and cannot cope without their support" (Carer Trust, no date).

This broad definition includes friends and multiple family members, including young carers. Previous research has highlighted the needs of young carers, for instance in academic attendance and performance, reduced social contact with family members, and poverty (Vizard, Obolenskaya and Burchardt, 2018; Somers, 2007). This indicates the need to support young carers and, due to their age, web-based resources could be a viable option (Ali et al., 2013). The research underpinning this PhD thesis is focusing on adult carers aged 18 years and above, however acknowledges the potential value of web-based resources for young carers in relation for future research.

1.2: Web-based support for carers

Under the Care Act (2014), primary carers are entitled to a carers assessment to determine the impact of the caring role on wellbeing and employment. The outcome of this indicates

carer supportive needs. Whilst the NHS provides some support to carers, for instance in referral to family interventions following their relative's first episode psychosis (FEP), the majority of support for carers is accessed through voluntary organisations. At present, carer and mental health charities and organisations offer access to peer support groups, counselling and information.

There has been a growing transition toward digital or web-based resources in healthcare, a process which is endorsed with the NHS Long Term Plan (2019). One example is the continued construction of mobile phone apps and web-based resources to promote mental health. Alternative available web-based support includes websites from healthcare and voluntary organisations, such as NHS Choices and Carer UK. Research has also investigated the impact of web-based interventions on carer health and has indicated positive effects on stress and knowledge regarding schizophrenia (Rotondi et al., 2010; Glynn et al., 2010). This is a growing research area with several ongoing research trials indicating the importance of frameworks towards developing web-based resources (Gleeson et al., 2017; Lobban et al., 2017).

However, there are problems associated with web-based support. For instance, professionals have reported concerns relating to the quality of web-based information and individuals have described difficulty understanding content (Berry et al., 2017; Sin, 2013). The National Literacy Trust (no date) reports that 16% of UK adults present literacy difficulties; an impediment indicating difficulty comprehending written text. This could indicate individuals may be unable to engage with web-based content and subsequently be disadvantaged regarding support provision. Further issues include negative appraisals of web-based resources, especially with older members of the public (Blackburn et al., 2004; Lal, Daniel and Rivard, 2018; Sin et al., 2018). An additional critique of web-based resources could be the assumption of uniformity regarding ability to access and applicability to needs. Concerning the availability of web-based resources, whilst this has been noted to have increased substantively (Office for National Statistics, 2017), there remains barriers to access, creating a digital divide. The UK government (2017) pledged to increase minority access (such as individuals with mental illness) to the internet and enlisted support from community organisations to fulfil this aim. However, this assumes that individuals want to increase technological access and that voluntary sectors have the capability to achieve this.

1.3: Research aims and questions

The aim of the research informing this thesis was twofold. Firstly, it was concerned with examining the impact and utility of internet/web-based support available to carers of individuals with ongoing SMI. Secondly, it aimed to build upon the research findings in order to inform construction of a framework/model which can provide structured guidance for the construction and evaluation of such internet/web-based support for carers of people with SMI.

The specific research questions relating to these aims were:

1. What typologies of web-based support are available for carers of people with SMI?
2. What is the perceived impact/utility of web-based support upon carer well-being and quality of life?
3. What are carers' views and perceptions of the factors which constitute effective web-based support for them?

In addressing these questions, a mixed methods approach within an overarching ethos of critical realism (Bhaskar, 1975) was employed. This constituted use of quantitative questionnaires to capture quality-of-life-related aspects, use of weekly diaries to capture web-based support use, and qualitative in-depth interviews to elicit richer aspects of participant experience. Taken together, this approach can be seen to match well with the research aims and questions outlined above.

Critical realism proposes the identification of generative mechanisms; defined as a theoretic explanation to an observable effect as opposed to a description achieved via significance testing. Critical realists also observe the actions of the individual and the appropriate contexts that trigger generative mechanisms. Thus, developing an understanding regarding generative mechanisms resulting in an impact on carer health, and the contexts underpinning mechanism activation, can be incorporated into a web-based intervention. More specific detail and discussion regarding critical realism and the identification of generative mechanisms will be included in chapter three.

The participants within the study were individuals in caring roles (a total of 8), who were invited to complete questionnaires, diaries and participate in qualitative interviews. In addition, 6 mental health professionals were invited to participate in qualitative interviews. The professional perspective was deemed as relevant and important, since

carers of those service users with whom they engage are often concurrently engaged with (or indeed directed to) web-based support resources.

My own background is as a researcher in the field of academic psychology. I am not a mental health professional in any therapeutic sense. I do have a close family member with a diagnosis of SMI and have been involved on a personal level with the informal care of family members at various times. This has provided me with some, though by no means definitive, insight and perspective regarding the role of carer.

This thesis culminates with the presentation of a framework for constructing and evaluating web-based resources aimed at offering information and support for those in caring roles for people with SMI. Importantly, this framework is aligned to the findings of the research informing this thesis, and thus the voices of the participants within this research.

1.4: The structure of this thesis

Chapter two: Presents relevant background literature within three key themes. Firstly, schizophrenia and psychosis as predominant SMIs are examined in terms of aetiology, diagnosis and risk. Secondly, literature concerned with the carers of this group is summarised in terms of impact upon carer health and the influence of available support. Finally, the role of web-based interventions and support is examined in terms of availability and typology.

Chapter three: Presents the underpinning conceptual framework for the research informing this thesis, together with a summary of the research design and methods employed within the study.

Chapter four: Presents the research findings with initial discussion in terms of the key emergent analysis of these findings. This chapter begins by presenting the descriptive and summative quantitative data from health questionnaires and weekly diaries measuring web-based resource use. Attention turns to the qualitative comparative analysis (QCA) which identifies causal conditions indicative of change in carer wellbeing and QoL. Following this, the thematic analysis of individual interviews with carers and professionals is presented. Interplays between subthemes and themes are addressed. Finally, this chapter presents identified generative mechanisms and relevant contexts that

enable or inhibit activation, identified from individual interviews with carers and professionals.

Chapter five: Builds upon the initial discussion of findings in chapter four, leading to the presentation of a carer needs-aligned framework, the key elements of which can be used to guide construction and evaluation of web-based resources aimed at supporting the carers of individuals with SMI. Following this, proposed tentative consideration of intervention components are introduced.

Chapter six: Considers the quality of the research underpinning this thesis and addresses researcher reflexivity.

Chapter seven: Concludes the thesis, revisiting the stated aims in terms of the degree to which they have been addressed. This chapter also considers implications for practice and further suggestions for future research.

Chapter 2. Background literature

2.1: Chapter overview

The purpose of this chapter is to provide a summary of the key salient literature underpinning this thesis. In doing so this chapter will provide a synopsis of the background research and will facilitate reader understanding of the context of the caring role, the impact of this role on carer health, and available web-based and non-web-based support for carers. It is not the purpose of this chapter to engage in an in-depth debate regarding key issues, such as diagnosis of mental illness, however some critique is included in outlining themes of previous literature. Whilst these issues can have an influence on carer health and circumstances, the focus of this thesis is to investigate web-based support for carers of an individual with schizophrenia or psychosis, and to develop a framework for the construction and evaluation of a web-based intervention.

First, this chapter will provide the search strategy used to search and identify key literature. The literature is presented and summarised in three themes; schizophrenia and psychosis, carers of individuals with schizophrenia and psychosis, and web-based support in healthcare. The key points from each theme will be addressed in relation to relevance to research questions and the focus of this thesis.

The first theme focusses on issues regarding schizophrenia and psychosis, including aetiology, diagnosis, stigma and considerations of risk. Reference to the impact of these issues on carers' and family members' health are noted throughout this theme. Attention moves to carers of individuals with schizophrenia and psychosis, outlining the growth of carers as experts by experience, difficulties with healthcare professionals and resulting impact of the caring role on carer health. Following this, non-web-based support for carers is considered with critique regarding effectiveness and availability. Finally, the third theme will consider the use of web-based support in healthcare. This theme will explore the expansion of technology and the available web-based support for carers of individuals with schizophrenia or psychosis. Focus will also include the notable concerns regarding web-based support in a healthcare setting, such as quality and risk of over disclosure.

2.2 Search strategy

The literature search was conducted from October 2015 to April 2019. Initial searches were completed at the onset of the research underpinning this thesis and were updated throughout the course of this project. Further intensive searches were performed following initial analysis of thematic findings. This stage of literature searching included new terms identified through initial analysis.

Nine databases were searched during the course of this thesis. Databases consisted of:

- ASSIA: Applied Social Sciences Index and Abstracts
- CINAHL
- Medline (via Proquest)
- Proquest Psychology Journals
- PsychARTICLES
- Wiley Online Library
- Social Care Online
- Social Services Abstracts
- Web of Science

An overview of key search terms included in this literature review are included in Table 2.1.

Table 2.1. An overview of key search terms implemented in literature searches

carer OR caregiver; family OR friend OR relative; parent OR mother OR father; sibling OR brother OR sister; spouse OR partner OR wife OR husband
schizophrenia OR psychosis
online OR internet; website OR webpage OR web; telehealth OR “tele health” OR tele*; online OR web OR website OR internet; “PC” OR computer OR “computer-based” OR “computer based”; “App” OR application OR mobile
support OR forum OR “help groups”; intervention OR information OR “self help” OR “self-help”; psychoeducation OR “psycho-education”; telehealth OR “tele health” OR tele*; “family intervention” OR “family psychoeducation” OR “family support”
Risk OR violence OR aggression
Biological OR genetics OR neurotransmitters
“experts by experience” OR expert OR information

Google Scholar was used to identify further publications and citations of key authors in the areas of interest. Reference lists from selected articles were also searched for additional relevant studies. Further articles were identified through journal search alerts through Proquest or Menderley referencing software. There was no timeframe included within this search, however it was expected that the majority of studies were likely to be from the year 2000 onwards given the technological focus and the increasing public access from this period.

Articles were reviewed if the key terms were included in the abstract, indicating relevance to the topic of interest. Articles were included based on the following;

- The population of interest was adult informal carers, family members or friends of an individual with schizophrenia or psychosis. This referred to an individual providing a caring role outside of that required for employment, for instance a care assistant.
- The focus was on assessing a single or multi-component web-based intervention for unpaid carers, family members or friends of an individual with schizophrenia or psychosis. This included psychoeducation, web-based forums or self-help.
- The web-based intervention primarily focused on or considered family member outcomes with those of the care recipient.
- Were available for review and in English.

Articles were excluded if the population of interest were paid carers of individuals with schizophrenia or psychosis (i.e. those providing care as a requirement for employment) or were young carers below the age of 18 years old. Published work which explored the impact of non-web-based interventions, such as medical or pharmacological interventions, were excluded. Further exclusion criteria included web-based interventions solely focused on care recipient outcomes but may indirectly impact carers, for instance an app issuing a reminder for medication.

2.3 Schizophrenia and psychosis

The International Classification of Diseases 11 (ICD-11) defines schizophrenia as an illness resulting in irregularities in mental modalities resulting in symptoms. Examples of symptoms include delusions, hallucinations and unpredictable or bizarre behaviour. In contrast, psychosis refers to the emergence of psychotic symptoms which vary in intensity

and type over short periods of time. Both schizophrenia and psychosis represent SMI, however schizophrenia refers to a specific mental health condition, whereas psychosis encompasses a broad range of diagnoses and symptoms.

The initial theme of this literature chapter will focus on schizophrenia and psychosis and is presented in three subthemes. The first subtheme will briefly outline key theories regarding the aetiology of schizophrenia, including relationship and communication theories involving family members and some consideration towards biological explanations. Attention moves to the diagnosis of schizophrenia and associated stigma towards ill individuals and their family members. Finally, this theme will consider risk associated with mental illness, the involvement of media and the difference in identifying this by carers and professionals. This theme will continue to refer to family members of an individual with psychosis as the key focus of this thesis.

2.3.1 Aetiology

Many of the initial theories regarding the development of schizophrenia have been critiqued for placing sole responsibility on family members. For example, Fromm-Reichmann proposed the role of the 'schizophrenogenic mother', stating that an emotionally-distanced relationship between mother and child can influence the development of psychological or social skills, therefore increasing the risk of developing of schizophrenia (Atkinson and Coia, 1995). Similarly, the double bind communication theory proposed that as a result of receiving paradoxical responses from parents (particularly mothers), individuals with schizophrenia are unable to allocate the correct response to contexts (Bateson et al., 1959). Although not specifically being attributed as a cause, Brown et al. (1962) identified the influence of family communication on schizophrenia, which he defined as expressed emotion (EE). Brown proposed five components of EE; warmth, positive remarks, critical comments, hostility and emotional over-involvement, however focus appears to have prioritised the latter three components. Research has highlighted the relationship between EE displayed by family members and schizophrenia or psychosis, with low EE being related to longer time to relapse (Koutra et al., 2015). This indicates that the provision of information and support to carers could influence the development and relapse of schizophrenia. The prominence of such family theories facilitated the institutionalisation of mentally ill individuals, resulting in segregation and little or no collaboration regarding care. This could further suggest an

impact on the carer's natural resistance and increase fear and stigma towards their ill relative. Furthermore, these theories could suggest that family members were a contributory factor towards the development of schizophrenia, increasing feelings of guilt and potentially influencing support and information provision.

Although not the focus of this thesis, it is important to acknowledge alternative theories of schizophrenia. For example, carers may be exposed to different theories of schizophrenia and this may influence perceptions of the illness and carer feelings of guilt or blame attributed to the care recipient. This could further influence how carers respond and react in the research situation. Birchwood and Jackson (2001) summarised biological explanations of schizophrenia, such as genetics and neurodevelopment. Birchwood and Jackson further noted that previous literature suggested a genetic link to schizophrenia, with the diagnosis of a close relative increasing risk of other family members experiencing psychosis. Additional biological explanations include neurodevelopmental theories such as the dopamine hypothesis, which gained prominence due to the effectiveness of antipsychotic drugs noted to inhibit dopamine production, and the post-mortem investigation of individuals with schizophrenia (Bebbington and McGuffin, 1988). However, Birchwood and Jackson suggested that accepting this hypothesis as a singular explanation for schizophrenia would be a simplification of a complex disorder. Shorter (2013) suggested that the explanation of psychiatric disorders was subject to fads that gained popularity due to interventions or treatments. Shorter noted that biological explanations originally gained prevalence in the asylum period before decreasing in popularity with the introduction of talking therapies. Talking therapies then became marginalised with the use of psychotropic medications in the 1960s which subsequently heightened popularity of biological explanations for mental illness. Theories that Shorter noted continue to be advocated by pharmaceutical companies. For families, a biological explanation for schizophrenia could reduce feelings of responsibility or guilt associated with diagnosis. This could also align with the popularity of the medical model portrayed in media, outlined later in this chapter.

Further aetiological explanations for schizophrenia include social factors, for instance adverse childhood experiences such as trauma or social deprivation. Tomassi et al. (2017) assessed the association between affective psychosis and childhood trauma, including severe sexual abuse by a relative and physical abuse. Results demonstrated a significant correlation between sexual abuse and affective psychosis, however there was no relationship with physical abuse. It is of note that this study also found a significant

correlation between psychosis and drug use, which has also been suggested as a causal factor to psychosis. Similarly, Fisher et al. (2010) found that individuals with psychosis were three times more likely to report severe childhood physical abuse from their mother, occurring under 12 years old, compared to controls. However, these authors noted that the majority of psychosis cases did not report abuse. Regarding, social deprivation, O'Donoghue et al. (2016) investigated the prevalence of FEP within a geographically-defined area in South Dublin, finding that the rate of FEP was higher in socially deprived areas. Similarly, a recent systematic review completed by these authors found that the presentation of psychosis was related to social deprivation, however there has been limited research into this economic status at birth (O'Donoghue, Roche and Lane, 2016). It is of note that when extraneous factors were controlled, this lost significance.

The stress-vulnerability model incorporates biological factors and psychosocial stress as contributory factors towards mental illness. Zubin and Spring (1977) suggested that an underlying biological vulnerability to the development of schizophrenia is triggered by stress generated by a life event, for example bereavement or divorce. The amount of vulnerability would indicate the level of psychosocial stress required to develop psychosis; for example, a high vulnerability would require a lower level of stress compared to an individual with low vulnerability. Birchwood and Jackson (2001) noted several critiques of the stress-vulnerability model, including the importance of understanding the contextual threat of a stressful situation. For example, whilst divorce can be seen as a negative life event, for some this could be positive. These authors also highlighted the danger of bias by only investigating the impact of life events in those who developed schizophrenia, and neglecting control groups. Finally, individuals can be diagnosed with schizophrenia without a previous vulnerability. Presently, there appears to be no universally-accepted definition for the development of schizophrenia, or indeed mental illness. Whilst the stress-vulnerability model provides a holistic explanation, the presence of schizophrenia in individuals without experience of a significant life stressor indicates the complexity towards the development of mental illness.

Thus far, this subtheme has presented schizophrenia as an illness. However it is important to acknowledge that there remains a debate regarding the existence and definition of mental illness. In his seminal historical overview, Foucault (1967) reported the confinement of the mentally ill in workhouses was an attempt to manage mental illness. Later these workhouses evolved into asylums. Foucault also noted the medicalisation of mental illness and the labelling of normality and pathology. Similarly, Szasz (1988)

argued that the suggested definitions of mental illness, in particular schizophrenia, failed to be upheld by scientific examination. Instead, Szasz suggested that schizophrenia was a form of social control by family members and society, which was enhanced by the use of medical terminology. As such, schizophrenia was used as an explanation for perceived unusual behaviour or thoughts that contrasted socially acceptable behaviours. Lang and Esterson (1990) examined family units of individuals diagnosed with schizophrenia, suggesting that family members used the illness as a source of control. For example, relatives viewed attempts of autonomy and behaviours that they perceived to be socially unacceptable as indicators of the illness. Lang and Esterson also reported that family members influenced their relative in an attempt to create their perception of a normal individual by informing them which views and memories were correct. The above arguments reject schizophrenia as a mental illness and link this to a form of societal control, indicating a social construction of mental illness.

2.3.2 Diagnosis and stigma

Schizophrenia is a mental illness characterised by positive and negative symptoms often occurring in adolescents aged 16 to 25 years old. However it can also occur in later life. Positive symptoms include delusions or hallucinations, whereas negative symptoms include anhedonia; these symptoms must be present for at least one month and not determined to be caused by external factors to be attributed to schizophrenia. Presently, diagnosis is determined by use of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association, 2013) or the International Classification of Diseases (ICD-11) (World Health Organisation, WHO, 2018). The use of diagnostic manuals can be argued to provide rigour and consistency with the diagnostic process. When reviewing change in diagnosis following a ten-year period, Heslin et al. (2015) found similar consistency between both diagnostic manuals, however the authors noted that this was slightly higher following diagnosis by ICD-10. In particular, schizophrenia was one of the most consistently-diagnosed mental illnesses after 10 years. Whilst this does demonstrate reliability in using diagnostic criteria, it is significant to note that new editions of these manuals have been released following this study, therefore indicates scope for further assessment.

However, the diagnostic process has been critiqued as providing a medicalised view of mental illness and therefore assuming the suitability of a similar process to physical

health. Johnstone et al. (2011) reported that this could imply a biological cause of mental illness when there remains no clear established derivation. These authors go on to state that if there is a biological causal factor to the development of mental illness, this is likely to be a contributory factor alongside psychological and social components, as proposed in the biopsychosocial model (Engel, 1977). Johnstone et al. go on to note that this is likely to reduce agency and empowerment, suggesting that recovery is dependent on the intervention and expertise of professionals, without input from the ill individual. Despite this, there are suggestions that the public and carers value the medical model due to the popularity of this in the media or their perceptions of this as an explanation towards their relative's distress (Heyman, 1998; Johnstone et al.; Outram et al., 2015). A diagnosis can provide clarification of the illness to others and allow access to treatment or financial benefits for patients and their family members (Cooke et al., 2017). However, a diagnosis of a mental illness can result in fear, misconceptions and instances of stigma from others or, in some cases, the individual receiving the diagnosis.

Reporting on the experiences of institutionalised individuals, Goffman (1961) reported that basic human rights that would have been granted prior to admission were revoked. One example of this is the requirement for mentally ill individuals to ask for permission for a cigarette, which would not have been mandatory when well. Goffman highlighted the removal of identity and the powerlessness experienced by individuals due to societal views of mental illness. Similarly, these views have been reported to influence carers who reported fear following their relative's diagnosis of an SMI due to misconceptions of risk (Labrum and Soloman, 2018). However, Goffman (1963) also noted that family members could experience stigma due to their relationship with the ill individual. This suggestion has been supported by research; for instance, carers have reported hiding the impact of symptoms due to attempts to reduce stigma and concern that their relative would lose close familial relationships as a result of disclosure (Onwumere, Learmouth and Kuipers, 2016a). Corrigan and Rao (2012) suggested that the awareness and agreement of negative stereotypes could lead to individuals applying these views to themselves, resulting in negative effects, such as isolation. Whilst Corrigan and Rao focused on individuals with mental illness, this could also occur in their family members (for example, Eaton et al., 2016).

There remain attempts to reduce the stigma associated with mental illness, such as government initiatives which have been facilitated by celebrity disclosures and creation of charities (Calaminus, 2013). One example of this is Bring Change to Mind (2010)

which was created by actress Glenn Close following the diagnosis of schizoaffective and bipolar disorder in two of her close family members. However, stigma towards mental illness is reported to still occur. For example, individuals with FEP described labelling due to stereotypical attitudes towards mental illness and concerns regarding violence and unpredictability (Gronholm et al., 2017). Therefore, web-based resources could be perceived as a useful and private method for acquiring support without the fear of judgement from others. Concerns regarding stigma could be a significant barrier to the access of information and support to promote carer health or assist in managing the caring role. The internet could provide access to information whilst ensuring privacy.

The concerns regarding stigma and the use of the medical model in diagnosing mental illness has led to suggestions of alternative methods. This includes the creation of a psychosis continuum similar to the autistic spectrum (Guloksuz and van Os, 2018). Cooke et al. (2017) suggested that an individual could move between wellness and mental illness during life stages. Ascribing to a continuum can promote normality of mental health and reduce stigma and the distress associated with a diagnosis by promoting the normality of experiences. Similarly, the use of formulations in Cognitive Behavioural Therapy (CBT) provides a "hypothesis about someone's difficulties which links theory with practice and guides the intervention" (p2) (Johnstone et al., 2011). This complements complexity theory by acknowledging multiple causal or contributory factors associated with the development of mental illness and uses this as an explanation for life circumstances, therefore attempting to move away from the medical model and provide an explanation for the illness.

However, it is of note to consider the value of receiving a diagnosis. For the individual with schizophrenia or psychosis, receipt of a diagnosis can facilitate access to organised treatment and support (Cooke et al., 2017). The classification of mental illness can also allow coordinated research into effective treatments and act as a guiding principle. For carers, a diagnosis can be perceived as an explanation for their loved one's illness and guide the search for information to support their relative. This could further facilitate the access of carer support, for instance the offering of family therapy following FEP (NICE, 2014).

2.3.3 Considerations of risk

There are a number of concerns regarding the implementation of community-based care for individuals with an SMI, especially relating to risk. The MH FYFV attributed this transition to the increased focus on human rights; however, others have suggested that this was the result of financial concerns (Hilton, 2016; Mental Health Taskforce, 2016). Scott (1998) commented on the resulting need to balance legislation between protecting the individual with an SMI and the members of the public. She stated that by maximising this concern, legislation could continue to increase fear and stigmatisation of mental health. However by minimising this, although this could promote patient autonomy, public risk could be increased. Scott indicated a need for balance for the public to receive information regarding risk associated with individuals with a mental illness without heightening distress and stigma.

Scott (1998) further claimed that public perception of risk could have been exaggerated following the media sensationalising high-profile cases; for example, Christopher Clunis or Andrew Jackson, who were diagnosed with schizophrenia and found guilty of murdering a member of the public. Cases such as this had a resulting impact on policy, risk assessments and mental health treatment. For instance, the murder of Ashleigh Ewing by Ronald Dixon brought about changes to the lone worker principles (NHS England, 2013). Not only could these high-profile cases increase fear in the public but could also have impacted on family members of an individual with schizophrenia. The availability of information and news stories via the internet could continue to influence this perception given the current unregulated status. This could indicate access to uncredited or biased resources, which is especially distressing to families who are seeking information regarding an initial diagnosis of psychosis.

Whilst negative media portrayal has associated schizophrenia with increased violence, individuals with this diagnosis are more likely to be victims of violent crime (Crabtree, 2017). Despite this, psychosis has been linked to increased violence and aggression (Douglas, Guy and Hart, 2009). Onwumere et al. (2014) reported that young male inpatients were more likely to be associated with violence, which was directed at individual carers, resulting in reduced self-esteem and higher levels of hostility. Carers were reported to experience verbal or physical threats, often finding this overwhelming and fearing the consequences of their relative's behaviour (Onwumere et al., 2018a). This could indicate that family members may require support in managing situations and in sustaining their health.

The MH FYFV reported that 90% of adults diagnosed with a mental illness were receiving care in the community. Consequently family members are taking more responsibility in caring for their relatives (Mental Health Taskforce, 2016). This has raised concerns regarding their ability to provide care possibly without the prior expertise or knowledge that healthcare professionals possess. Heyman (1998) noted the differences in identifying risk by family members of an individual with mental illness and professionals. He also suggested the media and its portrayal of the medical model was influencing family members' knowledge and expectations. Although this was suggested 11 years ago, it can still be relevant today. The availability of the internet has facilitated access to information (such as personal accounts from those who are experiencing psychosis) and media such as TV shows. However, Scott (1998) highlighted the value of family members in the identification of risk. Scott continued to reflect on the case of Andrew Jackson, whose family members had attempted to notify authorities of identified risk but were disregarded by healthcare professionals, which Scott attributed to the balance of power and professionals' previous difficulty working with Jackson. This indicates the value of collaboration with family members due to idiosyncratic knowledge and proposes the difficulty in assessing an individual within an hour-long session. Whilst collaboration is promoted through policy such as the Triangle of Care proposed by Worthington, Rooney and Hannan (2013), family members continue to report a lack of consultation in their relative's care (Onwumere et al*.,* 2016a).

2.3.4 Summary

In summary, this section has identified the following points;

- Initial theories of schizophrenia included family members as a contributory factor towards illness development. This could indicate the importance of providing information to family members regarding schizophrenia to influence its development and relapse. However, this could also suggest that family members may not have received adequate support or were treated judgementally as a result.
- While the diagnosis of mental illness has been criticised for providing a medicalised view of mental illness, family members reported preference for this approach. Although a diagnosis is required to access support, this can be related to stigma towards the individual with mental illness and their family members.

Not only could this have an impact on carer health, it could also prevent them from accessing non-web-based support.

- Psychosis continues to be associated with risk following sensationalised reporting by the media. Although individuals with schizophrenia are more likely to be victims of aggression, carers could also be encountering violence and aggression from their ill relatives. It is therefore important to acknowledge the possible impact on carer health and the need to provide information and support.
- There can be differences in the identification of risk by family members and professionals. However the importance of a collaborative approach is highlighted due to carers' idiosyncratic knowledge of the individual with schizophrenia.

The following chapter will outline literature relating to carers of individuals with schizophrenia or psychosis.

2.4 Carers of individuals with schizophrenia and psychosis

The second theme explores and summarises literature concerning carers of individuals with schizophrenia or psychosis, focusing on three key subthemes. Attention is first placed on the rise of experts by experience and the transition into collaborative-based healthcare. Focus then moves to an overview of the impact of the caring role on carer health, before summarising non-web-based support for carers of individuals with schizophrenia or psychosis. This theme concludes with a summary of the key points.

2.4.1 Experts by experience

The traditional model of healthcare places professionals at a higher, and therefore more powerful, position compared to patients and carers. For instance, Goffman (1961) drew attention to the treatment of asylum inmates, noting stigmatising attitudes and disempowerment through institutional regimes. Others have argued that mental illness was a method of social control to remove autonomy and promote conformity to perceived acceptable behaviour (Foucault, 1967; Szasz, 1988; Laing and Esterson, 1964).

In 1998, Heyman noted the increasing involvement of honorary experts in healthcare where patients and carers, who may lack medical or therapeutic experience, offer

idiosyncratic knowledge. Heyman stated that this perspective, when included with professional knowledge, could promote mutual learning for all parties. During the past 20 years, there has been continued transition to collaborative-based care that places carers and patients as experts by experience (Mental Health Taskforce, 2016). Experts by experience consist of individuals who develop knowledge and understanding based on their own experiences, whether this be experience of a mental illness (patient) or personal knowledge of their relative and the development of coping methods in dealing with encountered situations (carers). Experiential learning, as suggested by Kolb (2015), argues that education can be a continuous process where an individual will respond to a situation, reflect upon their response, conceptualise further responses and implement these in future situations. Collaborative-based care acknowledges the value of this knowledge and aims to incorporate these in healthcare decisions, for example the Triangle of Care that aims to create a therapeutic alliance between patients, carers and mental health professionals (Worthington et al., 2013). Consequently, patients and carers are now encouraged to take an active role in healthcare assessment, decisions and treatment, instead of being passive recipients of care, in keeping with the recovery model. The Northumberland Tyne and Wear (NTW) carer involvement strategy (2019) recognised the value of expertise via experience and aimed to place carers and patients as equal partners in service design and delivery. The strategy focuses on seven strategic ambitions including training, recruitment and selection, and communication. However, despite the growing recognition of expertise via experience, carers and patients reported referring to professional expertise when encountering some situations (Brooks et al., 2017); suggesting that the traditional balance of power may still exist in some contexts.

Previous research has indicated that professionals and carers can view collaborative-based care positively. Professionals value information exchange with carers, which may include content omitted by the individual with schizophrenia, and the carer's ability to identify indicators of relapse (Cree et al., 2015; Bradley and Green, 2017). Regarding family members, carers value being involved in decisions and having a voice concerning their relative's care, which has also been reported to be beneficial to carers' wellbeing (Department of Health and Social Care, 2018a; 2018b; Stanbridge, 2012; Susanti, Lovell and Maris, 2018). This research indicates that professionals could have access to more information that may guide treatment decisions and care concerning the individual with schizophrenia. This further suggests that carers find collaborative-based care valuable and empowering.

However, collaborative-based care includes several assumptions. First is that carers will and are able to provide care for their relative with schizophrenia, indicating that there may be limited choice in accepting this role (Seddon et al., 2006). This could cause difficulties if the carer is elderly or has their own physical or mental health concerns. Second, if judged to have capacity, patients have the right to exclude carers from involvement in their treatment or receiving information about their condition. Dirik et al. (2017) questioned whether patients feel obligated to include carers in treatment discussions and if this would reduce the patient input as a result. If excluded from involvement, family members could be providing care without receiving information to assist them in this role (Outram et al., 2015; Pinfold, Rapaport and Bellringer, 2007). The MH FYFV placed responsibility on healthcare professionals to manage this situation (Mental Health Taskforce, 2016); however, Cree et al. (2015) argued that this could place professionals in a difficult position. This is due to awareness of and the potential consequences of breaching professional obligations. Therefore, this could result in professionals being reluctant or unable to exchange detailed information about patient diagnosis and treatment to family members.

Carers have reported a need for information about mental illness, available services and professional roles (Kuipers, 2010; Outram et al., 2015; Sustanti et al., 2018). Lloyd and Carson (2005) found that carers sought information about responding to situations they encountered in the caring role. One example could be responding to hallucinations or paranoia in which carers reported to be seeking the correct way of overcoming these. This could suggest that receiving information could empower carers and increase their ability to cope with the caring role, impacting on the carer and the care recipient's health. Without receipt of information, the carer's ability to provide successful care would be inhibited with negative consequences on their health and relationship with healthcare professionals. This further suggests that carers implement a problem-solving approach to seeking information. Problem-solving was defined by D'Zurilla and Goldfried (1971) as:

> *"a behavioural process, whether overt or cognitive in nature, which (a) makes available a variety of potentially effective response alternatives for dealing with the problematic situation and (b) increases the probability of selecting the most effective response from among these various alternatives" (p108).*

In recognition of this, Mohr, Cuijpers and Lehman (2011) also noted the value of including a problem-focused approach and provision of solutions within web-based interventions. The implementation of a problem-solving approach is indicative of a needs-based approach for support. Roddy, Onwumere and Kuipers (2015) assessed the impact

and acceptability of a needs-based intervention for carers of individuals with psychosis. The intervention was designed in relation to identified carer needs and informed by family therapy interventions. Although this consisted of a small sample size, there was a reduction in carer distress and depression. Carers highlighted the value of a supportive intervention addressing their specific needs, indicating satisfaction with this approach. Alternatively, carer interventions have included content to encourage consideration towards personal needs (see Lobban et al., 2013).

Whilst collaborative-based care aims to increase carer and patient empowerment in healthcare, it could be argued that professionals remain in a more powerful position. For example, approved mental health professionals can detain users under the Mental Health Act (1983), allowing them to provide treatment to patients who are considered to lack capacity to consent or present a risk to themselves or others. If a family member is concerned about a relative, they are advised to request an assessment from their local mental health service; the outcome of this may contrast the carer's opinion, leading to frustrations with professionals and the health service. This situation, and the inability or reluctance in sharing information, could result in carers feeling unsupported and dismissed by professionals, believing that their knowledge was accumulated over time and via experience and observations (Onwumere et al., 2016b; Sin, 2013; Wainwright et al., 2015). In some instances, this could result in carers refusing support designed by healthcare professionals; this could be due to the belief they are unable to understand the carer's situation (Lloyd and Carson, 2005). Therefore, this could suggest the importance of carer involvement in the construction of support to ensure that this reflects carer needs and overcome potential bias.

2.4.2 Impact on carer health

The stress appraisal coping model proposes that the primary and secondary appraisal of a stressful event can determine coping ability (Lazarus and Folkman, 1984). Primary appraisal identifies the personal significance of the stressor, whereas secondary appraisal consists of the individual's perceived ability to overcome this; both of these appraisals indicate whether the stressor is seen as a challenge or a threat (Folkman et al., 1986; Folkman, 2008). The perception of the stressor results in a positive or negative emotional response and subsequent selection of a coping strategy: emotional, problem or meaning-focused coping (Folkman and Greer, 2000; Folkman, 2010). Szmulker et al. (1996) were

the first to link this model with carers of an individual with an SMI focusing on carer burden. This model suggests that the appraisal or prevalence of positive or negative caregiving experiences indicated the carer's coping ability and resulted in an outcome, for example the impact on carer health. Thus, proposing that influencing the appraisal of the illness and the caring role, whilst providing adequate resources, can influence the coping ability of the identified stressor.

Kuipers et al. (2010) suggested that although some carers may not need intensive support, even those with a positive relationship with their relative and positive appraisal of psychosis would require some support to assist them in their role. This further indicates that regardless of the impact of the caring role on carer health, support would continue to be useful for carers to sustain and promote their health. This could further assist carers in managing the caring role and provide care for their relative. Additionally, as the individual with schizophrenia can experience relapses, this could suggest that carer support needs may vary in accordance with their relative's health. In this sense, a web-based resource could provide accessible support when needed and without the restraints of non-web-based support, for instance waiting times or assessment periods.

Previous literature has also explored the association between the carer and the care recipient's health. Lobban and Barrowclough (2016) proposed a CBT-based model advocating that emotional responses were triggered by the behaviour from the other party. They suggested that carer behaviour could influence the development of the patient's schema and information-processing skills, which could be contributory factors to the development of psychosis. Similarly, the individual with schizophrenia's behaviour can result in a negative emotional response from the carer. The resulting behaviour is an attempt to manage negative emotions and is determined by the carer's perceptions of patient control over the illness. Research into EE has also suggested the impact of communication on both carer and care recipient health. Jansen et al. (2015) found that carers whose scores indicated high emotional over-involvement and critical comments reported higher rates of distress, anxiety, depression and coping difficulties. Patients whose family members scored highly in EE were rated higher in anxiety and depression (Kuipers et al., 2006). This relationship has also been identified by carers. For instance, Sustanti et al. (2018) reported that carers viewed their wellbeing as comprising of three key components: their family member's holistic wellbeing, carer involvement in their relative's care and support received from professionals. This previous literature suggests that providing individual support to carers may indirectly impact on the care recipient's

health as well as the targeted individual. As a result, carers have reported prioritising their relative's supportive needs over their own health (Askey et al., 2009; Murray, 2018). This suggests that carers may be failing to engage or utilise available support to assist them in promoting their emotional health. Not only can this impact on the carers' health, but this could also influence the care recipient.

2.4.2.1 Consideration of wellbeing and quality of life

Wellbeing was initially included in the World Health Organisation (1945) definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Dodge (2012) reported that despite the use of the term wellbeing within the public domain, there remains confusion relating to its definition, with this being used interchangeably with other terms. The author defined wellbeing as a balance between available resources and challenges encountered, with stable wellbeing being classified as having the psychological, physical and social resources required to overcome challenges. However, further definitions of wellbeing acknowledge both eudaimonic and hedonic perspectives which encompass psychological functioning or relationships, and subjective perceptions of happiness (for instance, Tennant et al., 2007).

However, there are aspects to consider regarding the subjective rating of wellbeing. Keyes (2005) reported that there is an assumption that the absence of mental illness would result in complete mental wellness. The author argues that wellbeing or mental health and mental illness are distinct concepts that are correlated. For instance, an individual may report subjective negative emotions which may not be applicable to a mental illness. Additionally, wellbeing naturally fluctuates during daily life and life events which is not indicative of a mental illness, for instance following divorce.

The consideration of the subjective perspectives on health appears to have encompassed defining and measuring QoL within the healthcare setting. Felce and Perry (1995) defined QoL as *"an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social and emotional wellbeing together with*

the extent of personal development and purposeful activity, all weighted by a personal set of values" (pp. 60-62). Integrating objective and subjective aspects, the authors also emphasised the importance of external context and the individual's assessment of this. The identified components interact with each other to generate change while also producing this individually. Whilst critiquing assessments of clinically-significant change in QoL tools, Crosby, Kolotkin and Williams (2003) noted the difference in meaningful change between patients and healthcare professionals;

> *From the point of view of the patient, a meaningful change in HRQOL may be one that results in a meaningful reduction in symptoms or improvement in function. In contrast, a meaningful change for the clinician may be one that indicates a change in the therapeutic treatment or in the prognosis of the disease. In defining clinically meaningful change, these perspectives may not always be in agreement. (pp. 396).*

A considerable amount of literature has been published on the impact of the caring role on carer health, with carers reporting negative emotions such as hopelessness, fear, grief, guilt and reduced wellbeing (Onwumere et al., 2016b; Wainwright et al., 2015). Hayes et al. (2015) found that half of carers met the criteria for a psychiatric disorder and showed reduced QoL compared to controls. Carers have reported lower mental compared to physical QoL, with lower QoL being related to higher burden and decreased psychological or spiritual values (Boyer et al., 2012; Foldemo et al., 2005; Gómez-de-Regil, Kwapil and Barrantes-Vidal, 2014). Whilst literature appears to prioritise primary carers, the caring role can affect the health of all family members. For instance, Sin (2013) found that siblings of an individual with psychosis reported feelings of isolation, embarrassment and often conflicting responsibilities between sustaining their own, their sibling's and other relatives' wellbeing. This indicates the importance of providing support to family members and carers to improve their mental health to avoid further deterioration or the risk of reaching crisis.

However, little attention has been given to the positive impact of the caring role on carer health. Carers of individuals with psychosis reported increased resilience, personal growth, understanding, and the development of a new perspective from undertaking a caring role (Sin et al., 2012). Sanders and Szymanski (2013) found that siblings of an individual with an SMI had significantly higher posttraumatic growth compared to controls. This suggests that the caring role can provide an opportunity for personal growth; however, support may be required to achieve or maintain this.

2.4.3 Non-web-based support for carers

The Care Act (2014) provided carers with the right to a free carer assessment and support for their identified needs, placing the accountability for this on local authorities. As individuals may not identify as a carer, the responsibility has been placed on professionals to classify primary carers and refer them for a carer assessment, however professionals reported some difficulty in doing so (NICE, 2014; Seddon and Robinson, 2015). A carer assessment identifies whether the caring role impacts on the carer's health, wellbeing, living arrangements and social activities. If this is judged to be the case, carers can have the right to support to promote their wellbeing, including access to technology such as computers or mobile phones, which suggests the continued transition to web-based resources. However, in only identifying the primary carer, this can exclude other family members who may be impacted by the caring role, such as siblings (Bowman et al., 2014; Sin et al., 2016a). This could result in these family members continuing to seek support via other methods, such as those available online.

Identified carers can receive free health checks and flu jabs through the NHS, which also offers a carer support service providing advice about care decisions and referral to other resources. Whilst providing a range of practical support, for instance information about benefits and carer assessments, this does not provide personal support such as counselling. Kuipers (2010) stated that there was no available healthcare service that prioritised carer needs and support often related to the patient's needs, citing the reason for this to be austerity and strained services. Reflecting on this piece, Onwumere and Kuipers (2017) reported that this continues to occur, indicating carers may have difficulty accessing personal support relating to their needs through the NHS.

Support for carers appears to be largely provided via carer or mental health charities or organisations, as opposed to a singular charity for carers of individuals with schizophrenia. These organisations are often commissioned by, funded by or work in partnership with the NHS and offer assistance such as providing information, peer support groups and, in some cases, counselling or respite care. However, many carers reported limited contact with carer services, leading to recent reports highlighting the need to promote their availability (DHSC, 2018a; 2018b). The lack of contact with services indicates that carers may be seeking alternative methods for support or difficulty accessing these resources; for example, concerns about leaving the person they are caring for, difficulty travelling to locations or managing other responsibilities such as employment. Consequently, these carers may be unable to access support and require an alternative medium, such as web-based resources.

NICE (2014) state that family members should be offered information and carer-focussed support, which can be incorporated into a family intervention. Family interventions aim to involve and collaborate with the family as a unit; viewing carers as partners in care as opposed to therapy subjects (Fadden and Heelis, 2010; McFarlane, 2016). For example, the Meriden Programme emphasises the importance of information sharing and provides stress management techniques to family members through face-to-face, web-based and mobile phone mediums (The Meriden Family Programme, no date). However, whilst this aims to include the whole family, siblings of individuals with psychosis stated reluctance to contribute to a family intervention due to concerns of increasing parental burden (Sin, 2013). Additionally, family interventions were reported to be poorly implemented in healthcare. Haddock et al. (2014) found that 3 out 187 family members were offered family therapy following their relative's initial diagnosis, indicating carers may experience difficulty accessing this support. Lobban and Barrowclough (2016) suggested a key barrier for family therapy was a lack of a framework regarding working with families, resulting in this being perceived by professionals as "unstructured, unpredictable and challenging" (p.199). Lobban and Barrowclough go on to suggest that the difficulty explaining psychosis and the inability to provide absolute answers can lead to carers feeling frustrated with services.

Psychoeducation is often associated with family interventions but is also considered a separate form of support. Largely consisting of information provision, this has been claimed to be a misleading term and often incorporates multiple domains, such as including CBT elements (McFarlane, 2016). As carers continue to report the need for

information (e.g. Kuipers, 2010), this could be perceived to be useful by family members. Despite this, Sin et al. (2017) found that psychoeducational interventions rarely focused on carer outcome measures. Studies that included these outcomes showed positive results, with psychoeducation having an impact on factors such as carer stress and depression, however there was a limited focus on carer wellbeing and QoL.

Psychoeducation is often provided to groups of carers, incorporating information provision with peer support. For instance, Yesufu-Udechuku et al. (2015) found that incorporation of psychoeducation and peer support improved the experience of caring and QoL, whilst reducing burden and distress. Peer support groups are also independent forms of support, allowing carers to offer advice and seek non-judgemental understanding from others encountering or experiencing similar situations. These groups can reduce isolation and can be seen as an economically valid form of support. Nilsen et al. (2014) found that for some members support groups were reported to be their only form of socialisation. However, members also acknowledged that listening to others' problems could be emotionally difficult.

Although support for carers is available, barriers such as funding restraints can result in difficulty accessing these or the loss of services entirely. Parity of esteem aims to place equal emphasis and care provision for mental and physical health. The MH FYFV acknowledged the disparity between mental and physical health, highlighting lack of mental health staff and funding, and pledged an additional billion pounds in funding in an attempt to create parity (Mental Health Taskforce, 2016). However, this report has placed priority on children's mental health and there appears to be limited attention placed on mental health carers, with any focus being placed on collaboration with professionals as opposed to addressing their support needs. This also focuses on individuals with FEP but does not include long-term carers who may be seeking support, suggesting that they may not receive the same standard of support as someone beginning a caring role. The NHS long term plan (2019) has pledged a further £2.3 million annual funding for mental health services by 2023/2024. This plan aims to maintain and develop new multidisciplinary services for mental health and provide a 24/7 community-based mental health crisis response. Whilst these proposals could assist the carer in management of the caring role, there remains no priority placed on carer health.

2.4.4 Summary

In summary, the key aspects of the above theme are as follows:

- Carers are taking a more active role in the healthcare situation and in caring for their relative following the acknowledgement of expertise by experience.
- Carers have reported a need for information to assist them in the caring role, however a barrier to achieving this could be patient confidentiality. If carers are unable to receive information from a healthcare setting, it is likely that they would attempt to find this online given the availability of web-based information.
- The appraisal of a situation or a potential stressor can influence carer health, indicating a need to influence these perceptions.
- Literature has highlighted the possible negative impacts of the caring role, indicating a need to provide support to carers. Not only could this improve carer health, but it could also affect the health of their relative.
- Carers' need for support could vary according to their needs and illness progression, indicating the potential usefulness of web-based resources that could provide quick accessibility without barriers of non-web-based support.

The following theme will present literature focusing on use of web-based resources in healthcare and for carers.

2.5 Web-based support to promote healthcare

The final theme of this literature chapter will present the use of web-based support within and outside a healthcare setting, before considering the influence of this on autonomy and user empowerment. This chapter will then consider the appraisal of and concerns surrounding the use of web-based resources before outlining previous research regarding online interventions for carers of an individual with schizophrenia or psychosis.

2.5.1 Use of web-based support in healthcare

Prior to the advent and accessibility of web-based resources, healthcare professionals were considered the primary source of health information. Whilst professionals continue to be a valuable source of information, the provision of this may be restricted to working hours and can prioritise the care recipient as opposed to supporting the carer. The use of

technology has been reported to promote user independence and empowerment by encouraging self-driven support seeking (Berry et al., 2017). Individuals can now access information directly via the internet with use of search engines, such as Google, that can provide millions of results in under a second. In 2017, the NHS website reported 525 million visits from users, indicating a high usage of web-based support regarding health promotion and information seeking (NHS Digital, 2017). Whilst this does not specify carer or indeed mental health-related searches, it is likely that some of these users would be carers seeking further information. For instance, Onwumere, Bebbington and Kuipers (2011) found that carers sought information following their relative experiencing FEP and, as such, the internet can be perceived as a valuable resource depending on the quality of the content available.

The NHS website (2016) provides information relating to schizophrenia and psychosis, for instance symptoms, causes and diagnosis. The content about schizophrenia includes a brief section for family members, including brief information about positivity, possible need for support and suggestions for assisting an individual who is suicidal. Users are directed to the Mind (no date) and Rethink (no date) websites for further information relating to carers. Additionally, users are referred to information regarding accessing mental health services. The NHS website also provides general information for carers and information about promoting their health. Presently, the NHS also provide some web-based resources such as information and downloadable PDF booklets (see Practical Guide to Healthy Caring, NHS 2016). Other forms of support provided may not be directly targeted towards carers and may be included amongst support for the individual with schizophrenia; for example, 'Hearing Voices and Disturbing Beliefs: An NHS self help guide' (Maunder et al., 2019).

Despite the value of web-based information, the quantity of this can influence engagement and adherence. For instance, a surplus of information, or information overload, can reduce usage of a web-based resource (Grudin, 2008). This could suggest that presentation of content could influence carer usage, regardless of perceived usefulness. The availability of interactive platforms, such as YouTube, has enhanced the presentation of health information. For instance, Lam, Tsianf and Woo (2017) investigated user access of Cantonese psychoeducational videos on YouTube, finding that a video providing information about schizophrenia and content for family members was viewed close to 5000 times within a year. This can indicate that users are seeking

information from a variety of different platforms as opposed to static information provided via website.

Eysenbach and Jadad (2001) noted that patients had equal access to information and suggested that this may result in professionals feeling uncomfortable working with patients with an equivalent knowledge base. This is also reflected in policy, as the Department of Health (DOH, 2014) stated that technology provides the ability to empower users to take ownership of their own health and transfer skills from professionals to patients. However, patients may also require assistance in finding appropriate support and therefore clinicians will need to be knowledgeable regarding technological developments and usefulness (Griffiths, Farrer and Christensen, 2007; Morris and Aguilera, 2012). Despite this, professionals reported appreciating prior research before beginning therapy, praising the ability for individuals to access information when needed and, in some cases, found this beneficial as a therapeutic tool (Berry et al., 2017). Further benefits include the ability to facilitate communication or discussions between carers, healthcare professionals and services (Lal et al., 2017). This indicates that technology can increase user empowerment, promoting a self-directed approach to information seeking, and is thus complementary to promotion of experts by experience in healthcare.

However, web-based resources have provided individuals with the ability to determine their level of engagement, such as deciding the amount of personal disclosure and the viewing of other's posts via social media (Naslund et al., 2016). Whilst this can be useful for promoting a self-directed approach to healthcare, it could also suggest that the use of web-based resources is dependent on user engagement, motivation and perspective. This could indicate that a user may cease using a web-based resource initially identified as not useful even though it could be a valuable resource; this could be more likely to occur due to the absence of an external influence, such as via a healthcare professional.

Carers have reported that web-based resources overcame geographical and time constraints, whilst increasing access to peer support and information via a variety of different platforms (Lal et al., 2017; Naslund et al., 2016). Whereas the accessibility of web-based resources were initially confined to the use of stationary computers, users can now access information and support at any location with an internet connection via smart phones or mobile phone applications (apps). Whittaker (2012) noted that individuals have instant access to personalised health advice and features such as reminders and monitoring to assist them in managing their health. This indicates that the availability of

emerging technologies can assist in the development of a self-driven approach to health information and support seeking. Although previous research has investigated the use of mobile phone apps in supporting individuals with schizophrenia, this does not appear to have been used as a medium to provide support to carers. Sin et al. (2018) conducted a systematic review into eHealth interventions for carers of an individual with long-term illness. Results demonstrated that carers viewed the flexibility associated with accessing web-based resources positively and valued the ability to communicate with other carers or professionals. eHealth was also shown to have subjective benefits on caring stress. Use of web-based resources could provide support when carers are reluctant to seek other resources due to stigma. For instance, Widemalm and Hjarthag (2015) found that stigma prevented youths whose parents were diagnosed with a mental illness from accessing support, however they praised the anonymity provided through online forums.

Whilst there are benefits associated with the use of web-based resources in healthcare, barriers can prevent access to this. For instance, carers reported a lack of time and familiarity in finding online information (Read and Blackburn, 2005; Lal et al., 2017). Although these barriers could occur in non-web-based support settings, the absence of an external influencer (such as a healthcare professional) could influence adherence to support.

The majority of web-based health information reviewed in the context of this research does not appear to be provided by the NHS. Other available resources are produced by third sector organisations or charities, such as Rethink or Carers UK, or by external organisations or individuals. Third sector web-based resources are largely provided via website or webpages and include information about mental illness, family members of someone with a mental illness or generic caring information. Some third sector organisations, such as Carer UK, also provide web-based forums where users can discuss problems or queries and receive support from individuals experiencing similar situations. Previous literature investigating the use of web-based forums by carers of an individual with a mental illness has found this to be a process of knowledge exchange and addressing queries raised by members, indicating the use of a problem-solving approach (Perron, 2002; Haker, Lauber and Rossler, 2005). Whilst this largely centred on active users, Perron also identified the ability for online forums to provide support to those who used this inertly due to the constant visibility of posts and responses, otherwise known as lurking. Regarding health benefits, use of online forums have been found to promote hope, provide understanding from communicating with others experiencing a similar

situation and reduce isolation (Trondsen and Tjora, 2014; Widemalm and Hjorthag, 2015). More examples of web-based communication can include mobile phone apps. Zhang et al. (2018) analysed 22,007 messages between families with a child at high risk of psychosis, finding that these prioritised topics based on school, family and medication.

Communication aspects have also been included in web-based interventions (for instance, Rotondi et al., 2010). Lederman, Bendall, Alvarez-Jimenez (2014) proposed the moderated online social therapy (MOST) model for a web-based intervention for youths diagnosed with psychosis. Within this model, the authors noted the importance of user discussion in developing an understanding of the illness. In reference to carer web-based interventions, this could refer to the development of the care recipient's experience as well as the caring role.

Recent policy has promoted the use of technology in providing healthcare and in supporting carers. For instance, the DoH (2014) stated support towards the development of economically-valid mobile phone apps to promote user mental health. Referring to the future of healthcare, the DHSC (2018c) stated that the UK has the potential to become a world leader in digital health and aimed to improve the use and quality of technology in healthcare, noting that present technology used is inadequate. However, this incorporation can be slow and difficult, often failing to keep pace with the continued development of technology. There is progression towards achieving this goal; for instance, Healios (no date), which is endorsed by NICE, provides family therapy via live-streamed sessions to family members and the person diagnosed with schizophrenia. However, this could still indicate that users seek and use external web-based resources that are not provided by the NHS or third sector organisations, which could increase the risk of carers accessing low quality resources.

2.5.2 Web-based support for carers of individuals with schizophrenia or psychosis

Previous research has largely focused on web-based resources for individuals with schizophrenia or psychosis as opposed to investigating the impact of this on carers' or family members' health (for instance, Alvarez-Jimenez et al., 2019). Few web-based interventions have assessed the impact of this resource on carer health, with others focusing on the usage or using this as a method of data collection (for example, see Stjernswärd and Hansson, 2013). This subtheme will provide an overview of web-based

interventions for carers of individuals with schizophrenia before considering possible disadvantages regarding the use of web-based resources in healthcare.

Preliminary work in this area was undertaken by Rotondi et al. (2005; 2010) who assessed the impact of a web-based psychoeducational intervention on health of individuals with schizophrenia and their family members. The intervention included educational materials (for example, stress management techniques) and three online therapy groups moderated by professionals; one for individuals with psychosis, one for family members and one for both parties. This suggests an interactive and personalised approach to seeking information and support from peers and professionals. Additionally, the use of individual groups can allow the ability to seek support from peers without concerns of judgement or causing distress to family members, whereas the availability of a shared group allows communication and the development of understanding of the other's experience. The intervention also provided a section to update users about upcoming news and events and allowed communication with healthcare professionals through an Ask the Experts section which provided the ability to anonymously post questions. These questions were later uploaded to a library, resulting in them being permanently available for later reflection when needed.

Although significant results were found in health, this was largely featured in outcome measures for individuals with schizophrenia as opposed to their family members. Regarding carers, there were no significant differences in outcomes following 3 months of usage compared to those receiving treatment as usual; however, family members showed increased knowledge concerning the prognosis of schizophrenia after one year (Rotondi et al., 2005; Rotondi et al., 2010). This could suggest that the web-based intervention may have been more suitable for individuals with schizophrenia as the primary model underpinning this intervention aimed to address problems experienced by individuals with schizophrenia when using web-based support (Rotondi et al., 2007).

Glynn et al. (2010) investigated a web-based intervention for family of military veterans and civilians diagnosed with schizophrenia. The web-based intervention included a discussion board, resource links to agencies, real-time chat and written or video-streamed information regarding schizophrenia. The real-time chat sessions occurred weekly before changing to bi-weekly, and focused on education review, achieving goals and problem-solving approaches. Additional groups for treatment and medication discussions and social support were offered for the first 6 months. This intervention investigated measures for both relatives and individuals with schizophrenia. Outcome measures for relatives

were distress and, only for the online group, family stress and perceived social support. There were no significant results for family members in the online group, but family relationship stress improved over time.

Focusing on siblings of individuals with FEP, Sin, Henderson, Pinfold and Norman (2013) proposed a randomised controlled trial (RCT) for a web-based intervention (eSiblings). This intervention assessed four conditions; psychoeducation only, online forum only, psychoeducation and forum, and control condition. The psychoeducational component was based on CBT, containing different information formats (text, audio and video) and included several homework tasks. This intervention also included links to alternative resources. Initial assessment of the usability of eSiblings reported that siblings accessed this resource fortnightly and valued this for information provision and interactivity, however they also reported difficulties in navigation (Sin, Henderson and Norman, 2014).

Expanding on this initial work, Sin et al. (2019a) developed a web-based resource for carers of individuals with psychosis implementing a participatory approach, featuring expert advisory groups. Accessible through computers and mobile phone apps, the COPe-support intervention is comprised of psychoeducation and forums. The informational components, provided via text or video, include content about psychosis, caring strategies and promoting carer health. Initial assessment of the prototype usability indicated carers viewed the web-based intervention positively, valuing information provision and ability to tailor this to their own needs (Sin et al., 2019b).

Chan et al. (2016) investigated a web-based psychoeducation intervention for Chinese carers of an individual with psychosis, incorporating online forums and information articles (for instance caring skills and self-care) which were available to be downloaded or viewed via YouTube. Articles included carer stories and interviews with individuals with schizophrenia. However, this study appeared to focus on assessing the usability of the intervention and the subjective effect on carer knowledge, and did not consider the impact on carer health.

Stjernswärd and Hansson (2017a) investigated a web-based mindfulness intervention designed for families of individuals with mental illness, including schizophrenia. Accessible through multiple devices, this encouraged carers to complete daily mindfulness exercises incorporating a time log and private diary. Findings were positive with a significant improvement in mindfulness, self-compassion and QoL. There was also

a significant reduction in perceived stress. Participants valued this approach and its flexibility but noted difficulty allocating time to it due to employment and management of the caring role (Stjernswärd and Hansson, 2017b). However, those who participated praised the ability to have time to themselves, suggesting that this promoted health and reduced rumination. Finally, this intervention was reported to promote the importance of focusing on their own needs as well as caring for the care recipient.

Recently, Gleeson et al. (2017a) proposed a social media-inspired intervention for carers of an individual with FEP based from the MOST model (Gleeson et al., 2017b). This intervention involved a psychoeducational therapeutic approach that focused on carer stress and strength promotion, enabling users to interact with each other and participate in peer support groups via an online café. Like social media, carers created individual profiles which could indicate an attempt to make this personalised and relatable to users. At time of writing, this trial is ongoing and assesses health-based outcomes such as stress, depression and coping via methods such as questionnaires or hair cortisol levels.

Similarly, Lobban et al. (2017) assessed a web-based intervention which consisted of 12 modules of written information (such as managing difficult situations), videos and self-reflection tasks. This intervention also provided the ability for carers to save internal and external links to information to provide easy access to relevant content, whilst also providing support through confidential messaging, forums and blog pages. Again, this trial is undergoing data collection and is assessing carer distress, wellbeing, support, beliefs, perceived coping and intervention usage. Other measures include the financial cost of resource provision and maintenance.

The above studies have largely focused on support provision through websites. However web-based support can also be provided via streaming to another location. For example, Hayley et al. (2011) assessed the impact of psychoeducation and a subsequent question-and-answer session provided face-to-face to family members whilst being streamed to an additional location. Results showed that carers demonstrated a significant increase in knowledge at both sites. Similarly, Absalom-Horny, Gooding and Tarrier (2012) assessed a family intervention delivered via a web camera to family members and an individual with schizophrenia who was detained. Family members achieved personal goals and showed an improvement in health, including reduced negative emotions such as stress and guilt. However, there were reported increases of fear for the future and sorrow that the authors attributed to an increased knowledge of schizophrenia.

The use of website-based interventions could provide quick access to information at any time, however it does not grant access to an individual or a professional for support. Whilst live streamed interventions give access to an individual, carers are likely unable to access the information following initial provision. Web-based interventions are often limited to a specific timeframe, restricted to a geographical area and may not be regulated or accurate. If a carer requires support outside of these parameters, they are likely to be using alternative forms of web-based support. However, research appears to have neglected this subject or has focused on young carers or parents of young children with a mental illness.

2.5.3 Concerns about web-based support

Eysenbach and Jadad (2001) noted that patients have access to an extensive range of information via web-based resources, and consequently professionals are now unable to filter this. Whilst this could be beneficial and provide access to a range of different perspectives, there could be concerns that carers may misinterpret or prioritise information that contradicts current recommendations, or suggest an unavailable treatment resulting in distress and frustration with services. Literature has highlighted concerns about an individual's ability to determine the quality of web-based resources without prior training (Berry et al., 2017; Gleeson et al., 2014; Naslund et al., 2016). This difficulty has also been raised by family members; for instance, siblings of an individual with psychosis reported the varying quality of and the difficulty understanding online information (Sin, 2013). An increased focus has also been placed on the prevalence and increased access of fake news; fake information or news stories that is designed to sensational or influence user perceptions. For instance, Allcott and Gentzkow (2017) recorded 159 million visits to low-quality websites providing information about then presidential candidate Donald Trump, indicating that this could have influenced voters. Access to incorrect or biased information could influence appraisal and understanding of the illness. The consequences of this could be a delay seeking initial support and diagnosis, conflicts with healthcare professionals, increased feelings of isolation due to stigma, and feelings of distress.

Wright (2012) stated that quality assessment would remain a major concern but suggested continued improvement due to increased experience and knowledge. Others have stressed the need for reliable, evidence-based resources that are regularly updated and accessible

for families from varying educational backgrounds (Clarke, Chambers and Barry, 2017; Lal et al., 2017). There have been some attempts towards achieving this, for example the NHS App Library (no date) lists evidence-based mobile phone apps for users to download and use to achieve for their health needs. Presently, there does not appear to be a specific caring app; however available apps could be useful for carers, for example those addressing anxiety or stress management.

The digital divide can include difficulty accessing or using technology due to lack of availability, age, or limited technological literacy. Whilst policy suggests that technology is economically advantageous in healthcare provision (e.g. DoH, 2014), for the user there are a number of costs relating to purchasing a device, acquiring an internet provider and antivirus protection (Wright, 2012). Further expenditure could occur with technological development and the introduction of new models, eventually resulting in the used device being out of date and the user unable to access updated support. Additionally, there remain areas with limited access due to poor networks. The House of Commons (HOC) (2018) considered the availability and speed of superfast broadband in the UK. Internet speed is considered through quantity of data downloaded or uploaded per second, measured as megabits per second (Mbps). Superfast broadband is classified as the ability to receive an internet speed over 24 Mbps, with an adequate speed being considered at 10 Mbps. The HOC noted that whilst the majority of the UK have access to superfast broadband, 2.4% are unable to receive 10 Mbps of internet speed with a higher prevalence of this in Scotland and Wales. This could suggest that, despite the wider accessibility of technology, there remains disparity in access to web-based resources. Thus, some individuals will be unable to access this support and could risk being excluded from the continually-growing technological-driven society.

Blackburn, Read and Huges (2004) investigated factors regarding carer internet use, finding age was the strongest predictor with younger carers being more likely to access the internet. This indicates that older carers may experience difficulty using web-based resources compared to digital natives. This was later supported by Read and Blackburn (2005) who found that age was related to difficulties using technology or finding online information, thus creating barriers to accessing the internet. However the assumption that only younger individuals would utilise web-based resources could constitute to an ecological fallacy, i.e. prior assumptions supported by probabilistic statistics resulting the rejection of evidence indicating the contrary (Heyman and Henriksen, 1998; Hill and Machin, 1998). For instance, the assumption that an older carer has limited technological

literacy despite the individual owning and being proficient using a Smartphone. This indicates that older individuals may not be referred to web-based resources due to professionals' assumptions regarding abilities and preferences. Whilst older individuals are reported to be less likely to access the internet compared to the younger demographic, recent statistics have indicated that this is gradually increasing (Office for National Statistics, 2018).

Szalma and Hancock (2008) described technology as a paradox, stating that it was initially created to assist with timely task completion, however poorly-designed systems and the difficulty using technology impede this. One suggestion for individuals who struggle to use technology could be to provide training to increase confidence and usage (Berry et al., 2017). For instance, Dow et al. (2008) provided older carers with computers and training, finding that carers showed increased confidence using the internet and reduced depression and loneliness. Although this had a small sample size and therefore significance testing was not possible, this indicates that acknowledging and providing technology and support could increase the likelihood of and confidence in using web-based resources. However, this is labour intensive and may not be possible due to funding restraints of organisations.

This digital divide is considered in some policy documents, which state the need to develop usable technology for individuals with mental or physical health difficulties and limited digital literacy (DHSC, 2018a; Department for Digital, Culture, Media and Sport, DCMS, 2017). Solutions to minimise the digital divide for these populations include the development of skills addressing the causes of digital exclusion, and collaboration with private and third sector organisations. However, this appears to make the assumption that carers, patients and professionals are willing and would like to engage in web-based support. Young carers reported the need to include links to non-web-based resources in an online intervention, considering this as having the ability to impact carer's life (Elf, Skärsäter and Krevers, 2011). Referral features have been included in web-based and non-web-based carer interventions (Lobban et al., 2017; Lobban et al., 2013). Researchers have also noted difficulty recruiting participants for studies involving web-based support, suggesting that this could be the result of the preference for face-to-face support and the novelty of technological support leading to many participants feeling unable to contribute (Lal et al., 2017; Sin et al., 2018). Similarly, professionals have reported web-based resources as being an additional burden to duties and highlighted concerns that these will

result in reduction and replacement of existing services (Berry et al., 2017; Clarke et al., 2017; DoH, 2014).

There is some concern that communication through web-based platforms could be difficult due to the inability to view facial cues, leading to difficulty understanding implications or user intent. For instance, sarcasm can be indicated through tone of voice or facial expressions, which is difficult to convey with text-focused web-based information, and could result in misunderstanding. Mohr et al. (2011) considered this to be a short-term barrier and noted the adaptation of web-based communication to convey intent, for instance emoticons (portrayal of mood or facial expressions using text) or graphic interchange format (GIFs) (web-based image). An additional solution could be the use of live video communication, such as Skype or FaceTime, however the quality of these could influenced by internet bandwidth or connection.

The growth of web-based resources have introduced new challenges and risks for patient safety and privacy. Posting about experiences of mental illness and treatment could be beneficial for the individual providing this and for other viewers; for instance, reducing isolation and increasing understanding. However, there is a risk of over disclosure where the user shares detailed and identifying content. Suler (2004) classified this as a disinhibition effect, defining this as the over sharing of personal information due to perceptions of anonymity using technology or web-based platforms. Whilst this could have notable concerns regarding the confidentiality of carers and their relatives with an SMI, others have suggested that over disclosure could provide an opportunity to examine and begin to address personal circumstances and problems (Barak, Boniel-Bissim and Suler, 2008).

One example of over disclosure could be use of web-based forums, suggesting the need for moderation (Berry et al., 2017). Moderation could be provided by healthcare professionals or volunteers, however again this can be labour intensive and costly. Whilst it could be argued that these risks have always occurred in a healthcare setting, the wide availability of posts and remoteness associated with technology could increase the danger of resulting damage. Moderation could limit the damage of over disclosure, identify users at risk of self-harm or suicide and provide access to support at a vital time. Reamer (2018) highlights the importance of developing protocols to assist professionals in managing these situations, especially as this may include substantial geographical distances. However, the use of moderation could restrict usage, especially if the carers have negative perceptions of healthcare.

Within the supportive accountability model, Lederman et al. (2014) considered the safety and privacy of web-based interventions, suggesting the value of collaborating with users to monitor the resource and use of an automated system to identify terms associated with risk. These authors further proposed the provision of emergency information, user referral after initial assessment by health carer professionals and the use of security measures to promote privacy, such as passwords and ability to conceal profiles. However, Doherty, Coyle and Matthews (2010) stated that users would require assurance of privacy and discretion using web-based health interventions. This could indicate that users may have limited trust in the security of web-based resources. This distrust could be further increased with media reports of data breaches or the hacking of websites. For instance, the NHS cyber-attack where a computer virus prevented access to health records or computer use until a ransom was paid (Telegraph, 2017). As a result, users may be unwilling to engage in web-based resources without a guarantee of anonymity or safety in use.

The above concerns regarding web-based support could further enhance carer and professional negative attitudes or appraisals towards web-based resources in healthcare. Consequently, this could prevent successful implementation in the healthcare setting, which could in turn result in failure in uptake and enduring effectiveness (Vis et al., 2018; Murray et al., 2010). Normalisation Process Theory (NPT) focuses on the implementation or normalisation of health interventions in healthcare practise (May and Finch, 2009). NPT is comprised of four components; coherence (referring to the distinctiveness of the resource and user sense of purpose), cognitive participation (denoting the views of the population and probability of utilising the resource), collective action (signifying compatibility with practise), and reflexive monitoring (indicating perception of usefulness from initial use). This theory suggests that carers and healthcare professionals would need to identify the use and purpose of the web-based resource, view these resources as useful and have the ability to access these. Furthermore, the web-based intervention would need to be compatible with current available support for carers.

2.5.4 Summary

The key points of the above subtheme can be summarised as follows;

- The availability of web-based resources and information have been reported to promote user empowerment by encouraging self-directed support seeking. Web-

based resources can also include interactive components, such as informative videos, and online forums promoting communication between individuals with similar experiences. The continued development of technology, such as mobile phone apps, have increased the accessibility of web-based support for health.

- Web-based resources can provide available support to carers and increase empowerment.
- There are concerns regarding professionals' views of the increased availability of and access to web-based information, however research has suggested this could be beneficial for collaboration with carers and patients. Research has highlighted the value of web-based resources for carers but also acknowledges the existence of barriers, such as age and technological literacy. Despite the increasing popularity of the internet, there remains a digital divide that may prevent usage.
- There continues to be a transition into digital-based healthcare by policy. Whilst some web-based resources are provided by the NHS and by charitable organisations, other resources available may not provide quality information.
- There has been limited focus on assessing the impact of web-based interventions on the health of carers of an individual with schizophrenia or psychosis. Those which are available have largely focused on an intervention provided via a website. These studies have suggested that web-based interventions can have some impact on carer health, however fail to consider alternative types of online support that carers may already be accessing.
- There remains concerns regarding the use of web-based resources in healthcare with these including the quality of information available and new challenges regarding risk and promoting safety and privacy online.
- There appears to be a negative appraisal of web-based resources, with carers indicating a preference for face-to-face support and offline resources.

2.6 Chapter summary

This chapter has presented three key themes regarding schizophrenia and psychosis, carers and the use of web-based resources in healthcare. With the movement towards

collaboration and the acknowledgement of experts by experience, carers are taking an active role in caring for their relative and promoting their own health. This could result in carers attempting to manage situations with limited previous knowledge, such as the identification of risk. Carers continue to report a need for more information and may encounter barriers receiving this in a healthcare setting, for example because of patient confidentiality.

Caring for an individual with schizophrenia or psychosis has been shown to have an impact on carer health and wellbeing. Carers have reported encountering stigma and isolation that could impact on their willingness to seek support for their role and in managing their own health. There is also a relationship between carer and care recipient health, suggesting that by improving one party's access to support, this could have an effect on the other. Whilst some support is available for carers, there are barriers to accessing this, such as funding restraints.

Therefore, carers could be seeking web-based information and support to assist them in managing their caring role and to promote their health. Benefits of web-based support include accessibility at any time or location with an internet connection, however there are barriers including technological literacy and age. Other factors include the appraisal of web-based support and the consideration of risk and over disclosure. Based from this, it is important to assess carer use of web-based support and the impact of this on their wellbeing and QoL.

Chapter 3. Research design and approach

3.1 Chapter overview

This chapter has two objectives; first, it presents the conceptual framework underpinning this thesis. In doing so, this chapter defines conceptual frameworks and summarises the importance of inclusion in the research process. The conceptual framework outlines the ontological approach of critical realism.

Second, this chapter discusses the methodological and design issues relating to the research informing this thesis. This begins by considering a mixed methodological approach, consisting of qualitative and quantitative data collection. The chapter then outlines QCA and thematic analysis. Focus moves to detailing the sample, recruitment methods, and ethical issues.

3.2 Conceptual framework

Conceptual frameworks are defined as a "guide and ballast" for the research process, illustrating their importance (Ravitch and Riggan, 2012). In this sense, Ravitch and Riggan defined conceptual frameworks as "an argument about why the topic one wishes to study matters, and why the means proposed to study it are appropriate and rigorous" (p7). Thus, conceptual frameworks highlight the importance of the proposed topic and demonstrate the relevance and alignment of research questions with the methodological and analytical approach undertaken in the research. Similarly, although not specifically referring to a conceptual framework, Crotty (1998) noted the relationship between ontological and epistemological stances of methods selected to investigate a phenomenon. Therefore, conceptual frameworks could be a means of ensuring study quality and provide justification regarding research decisions.

Ravitch and Riggan (2012) postulate three components to conceptual frameworks; personal interests, topical research and relevant theoretical frameworks. Personal interests comprise of the researcher's interests, position to the research, potential biases and epistemological stance. The authors go on to define topical research as previous work focusing on the subject of interest that assists the identification of gaps and prior methodological approaches. Finally, theoretical frameworks identify the interrelationships within the research focus.

It is useful to revisit the research questions at this stage:

1. What typologies of web-based support are available for carers of people with SMI?
2. What is the perceived impact/utility of web-based support upon carer well-being and quality of life?
3. What are carers' views and perceptions of the factors which constitute effective web-based support for them?

The above research questions encompass the experiences and perceptions of carers whilst also aiming to produce a framework to construct a web-based supportive intervention. The complexity of the focus of interest led to the choice of a mixed methodological research design, incorporating quantitative and qualitative methods. To establish a theoretical framework which logically and coherently underpins the use of mixed methods, it is important to establish the ontological position underlying their use. In this case, critical realism.

3.2.1 Ontological and epistemological stance

Ontology is defined as the study of existence and the organisation of reality, whilst also encompassing the relationship between reality and human involvement (Crotty, 1998; Braun and Clarke, 2013). The typologies of ontology are depicted on a continuum with empiricism and interpretivism situated at both ends. Empiricism, focused with positivism and a quantitative approach, assumes the existence of a true reality independent of human influence. In contrast, interpretivism, which includes social constructionism, proposes that reality is constructed by individual understanding about the world and communications surrounding this; therefore, is largely associated with qualitative research (Elder-Vass, 2012). In this sense, there is no objective reality and therefore ontology interlinks with epistemology. Crotty defined epistemology as "the theory of knowledge embedded in the theoretical perspective and thereby in the methodology" (p3). Or, to put it simply, "how do we know what we know?" (p9). Researchers, such as Braun and Clarke, situated critical realism in the centre of the ontological continuum and therefore align this with mixed methodological approaches.

The key principles of critical realism as proposed by Bhaskar (1975; 1998) are as follows;

- The intransitive and transitive reality

- The separation of epistemology and ontology
- The existence of a stratified reality
- The identification of casual mechanisms by implementing a process of retroduction.

Critical realism incorporates scientific knowledge with human influence by suggesting the existence of a stratified reality (Bhaskar and Lawson, 1998). Similar to empiricism, Bhaskar (1975) proposed the existence of an objective reality that is independent from individual influence and therefore would exist regardless of human awareness (referred to as the intransitive reality). However, Bhaskar also advocated for a transitive reality defined as individual perspectives and perceptions of the objective reality that may become close to reflecting this over time. In this sense, critical realism has been reported to be complementary to social constructionism (Elder-Vass, 2012). However, Bhaskar argued that ontology could not be determined by epistemology, and in doing so, constituted it as an epistemic fallacy.

Bhaskar (1998) proposed that the stratified reality is made up of three levels; empirical, actual and real. Plato's Analogy of the Cave (as described by Peterson, 2017), can be a useful example for the explanation of the proposed stratified reality. The analogy describes several prisoners chained so that they can only face a wall in front of them. Unbeknown to the prisoners, there is a wall behind them where villagers often cross, and before this is a large fire that illustrates the shadows of the villagers onto the wall. The prisoners converse with each other to develop an understanding of the shadows based on their perceptions until one escapes and discovers the truth. The empirical level consists of events experienced by the individual or the population; i.e. the observation of the shadows on the wall and the resulting communication. The actual level refers to all effects regardless of human perception; for instance, the fire, the villagers, the shadows etc. Finally, the real level comprises of generative mechanisms that provides an explanation for observed effects (Pawson, 2008); such as the light from the fire and the villagers crossing the bridge that result in the shadows.

Critical realists argue that observable effects following the implementation of an intervention provides a description as opposed to an explanation of causation, therefore implementing a black box approach (Dawkin et al., 2015; Pawson and Tilley, 1997). Bhaskar (1975) argued that closed systems and experimental control is unattainable in social research due to human agency, which can influence circumstances and adherence

to interventions. Thus, Bhaskar argued the importance of identifying causal or generative factors of outcomes occurring within the real level of the stratified reality. As stated by Houston (2010):

> *"...merely knowing that event 'C' had been followed by event 'D' was insufficient... What was important was gaining an understanding of how 'C' gave rise to 'D'" (p82).*

Mechanisms are only accessible via use of theory generated as an explanation of the effect (Blom and Morén, 2015). In this sense, interventions and the resulting outcome can be observed or measured using validated scales. However, the mechanisms generating the effect cannot be observed and must be theorised. In doing so, critical realists propose a process of abduction or retroduction; classified by Blorm and Morén as the identification, formulation and analysis of generative mechanisms.

Pawson (2008) described the identification of mechanisms as:

> *"...as comfortable as a pair of baggy old socks but for some reason social research has tried to walk on higher heels" (p15).*

This suggests that the theorising of generative mechanisms is commonplace within research, with researchers aiming to provide a theoretical explanation to observed effects. Pawson goes on to highlight the importance of individuals in implementing generative mechanisms. Whilst the programmes or interventions offer the potential of an outcome, it is the individual that triggers this (Pawson and Tilley, 1997). For example, a telephone can make phone calls, however this only occurs if an individual implements this process. Thus, the interactions between context and generative mechanisms implement change. Mechanisms were reported to derive from the individual, such as choice in usage, or the intervention. Using the example of CCTV in a car park, Tilley and Crime Prevention Unit (1993) advocated that this intervention demonstrated a focus on crime prevention and therefore indicated an increased risk of apprehension of offenders. However, Pawson and Tilley argued the significance of contexts interacting with mechanisms; if a car is parked outside of CCTV range, the effects will not occur. Therefore, an intervention will only be successful if this produces a mechanism within the correct context. Evaluations should thus "be demonstrating what it is (M) about the program which works for whom in what conditions (C)" to produce an outcome (p72), otherwise presented as CMO configurations (C + M = O). See figure 3.1, for a visual depiction.

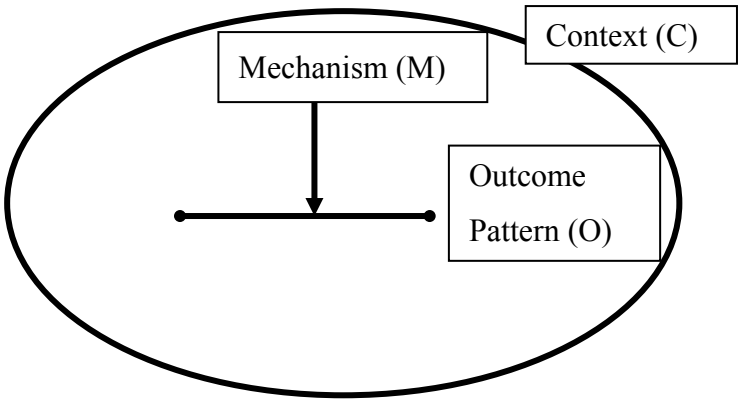

Figure 3.1. An illustration of generative causation regarding contexts, mechanisms and outcomes (Taken from Pawson, 2008).

Dawkin et al. (2015) reported on the challenges differentiating between contexts and mechanisms in evaluation research. These authors proposed the following amendment to the CMO formula, highlighting the separation of mechanisms generated via the intervention or through human reasoning: M (Resources) + C→M (Reasoning) = O. The identification of generative mechanisms and the contexts in which these occur will be further considered in Chapter five.

Critical realism has been aligned to complexity theory. Byrne (2005) defined complexity theory as the:

> *"interdisciplinary understanding of reality as comprised of complex open systems with emergent properties and transformational potential" (p97).*

By 'complex', complexity theory argues against the assumption of a simple linear reality by advocating the interaction of various non-linear causal factors attributed to an outcome (Byrne, 1998). In doing so, it supports the importance of investigating the complexity of the social world and therefore assumes the existence of complex systems (Uprichard, 2011). Plsek and Greenhaugh (2001) defined complex systems as the interaction between individual agents, where the change in one agent may alter the context for others. This change could be predicted or could be unexpected, therefore indicating the complexity involved. Thus open systems have been described as nestled components with the potential for interaction due to fuzzy boundaries, and are therefore not hierarchical systems (Byrne, 2003; 2011). Plsek and Greenhaugh also noted that memberships to systems can fluctuate and also overlap. In later work, Byrne (2013) directly linked this to QCA and suggested that cases are complex systems in that changes depend on the whole and the interaction between other cases and complex systems.

Although the above paragraph has highlighted the role of multiple non-linear causal conditions in producing an outcome, it is also important to clarify that complexity theory acknowledges the existence of multiple trajectories. Therefore, this highlights the possibility of causal conditions cancelling out other potential outcomes (Byrne, 1998). However, Byrne (2011) noted that complex systems are not chaotic in that change is minor and often the result of fluctuations in key factors. Furthermore, Haynes (2018) stated that, whilst disruptions are more probable within complex domains, this differs from chaos, which consists of instability. Using the example of psychotherapy, Haynes suggested that it could be difficult to determine an effect across different conditions (such as location) within complex research. However, he proposed that it could be feasible to identify aspects facilitating or preventing the preferred outcome, whilst acknowledging that these could be disrupted. This indicates compatibility with a critical realist perspective; further supported with the consideration of the impact of context, such as time, on causal conditions. For example, current causal conditions relating to the implementation of a web-based intervention could differ from those present a decade ago due to the continued development of technology and flexibility in use.

Although the similarities between critical realism and complexity theory have been noted, there have been limited attempts to converge these into what Byrne (2011) defined as complex realism (Williams and Dyer, 2017). Key examples of congruence between these approaches include the identification of multiple causal factors or mechanisms, the acknowledgement of human interpretation and agency, and the dependence on context (Byrne, 1998; 2005; 2013a). Having identified the compatibility of critical realism and complexity theory, the fit with a mixed methodological approach will be identified later in this chapter.

3.2.2 Development of the conceptual framework

Having established the importance of a conceptual framework within research and outlined critical realism and complexity theory, attention will now turn to the presentation of the conceptual framework underpinning this thesis. Ravitch and Riggan (2012) advised that conceptual frameworks are developed based from the researcher's personal interests, topical research and theoretical frameworks. Thus, these points are addressed below in relation to assembling the conceptual framework.

Firstly, regarding personal interest in the research area, I have held an interest in mental health for a number of years, deriving from the diagnosis of a close family member with an SMI. The interest in carers and family members of an individual with a mental illness developed following the application to the PhD studentship and subsequent searches of literature. Conducting this thesis allowed an opportunity to contribute to a growing level of understanding regarding carer supportive needs and the potential to make a difference.

Secondly, previous literature, as detailed in Chapter two, has highlighted the possible negative impact of the caring role on carer health relating to the stress, appraisal, coping model. Further contributory factors include the perception of the risk posed by their ill relative and the stigma associated with a diagnosis of psychosis or schizophrenia. The transition to perceiving carers as experts by experience has allowed carers to take a self-directed search for information and health support seeking, however this could also indicate increased difficulties with healthcare professionals and feelings of isolation. Although support is available for carers, difficulties accessing this could result in carers using web-based resources for support needs. Previous web-based interventions have demonstrated some impact on carer health, however this is limited to location and a specific time point. There also remains scope for further investigation of mechanisms relating to web-based support use. This summary is incorporated within the conceptual framework under previous knowledge and experience.

Finally, critical realism has been outlined as the underpinning theoretical framework for this thesis. Critical realism and complexity theory can be seen to coincide with the research questions. Regarding complexity theory, this can assess the perceived impact/utility of web-based resources by identifying key casual conditions relating to the use of this support and the difference in carer wellbeing and QoL following 6 weeks of usage. Critical realism complements the investigation of the views/perceptions of web-based resources by facilitating the identification of mechanisms. These mechanisms were used in the development of a framework towards a web-based supportive intervention for carers of an individual with schizophrenia or psychosis.

Overall, these components compose the conceptual framework underpinning this thesis displayed in Figure 3.2.

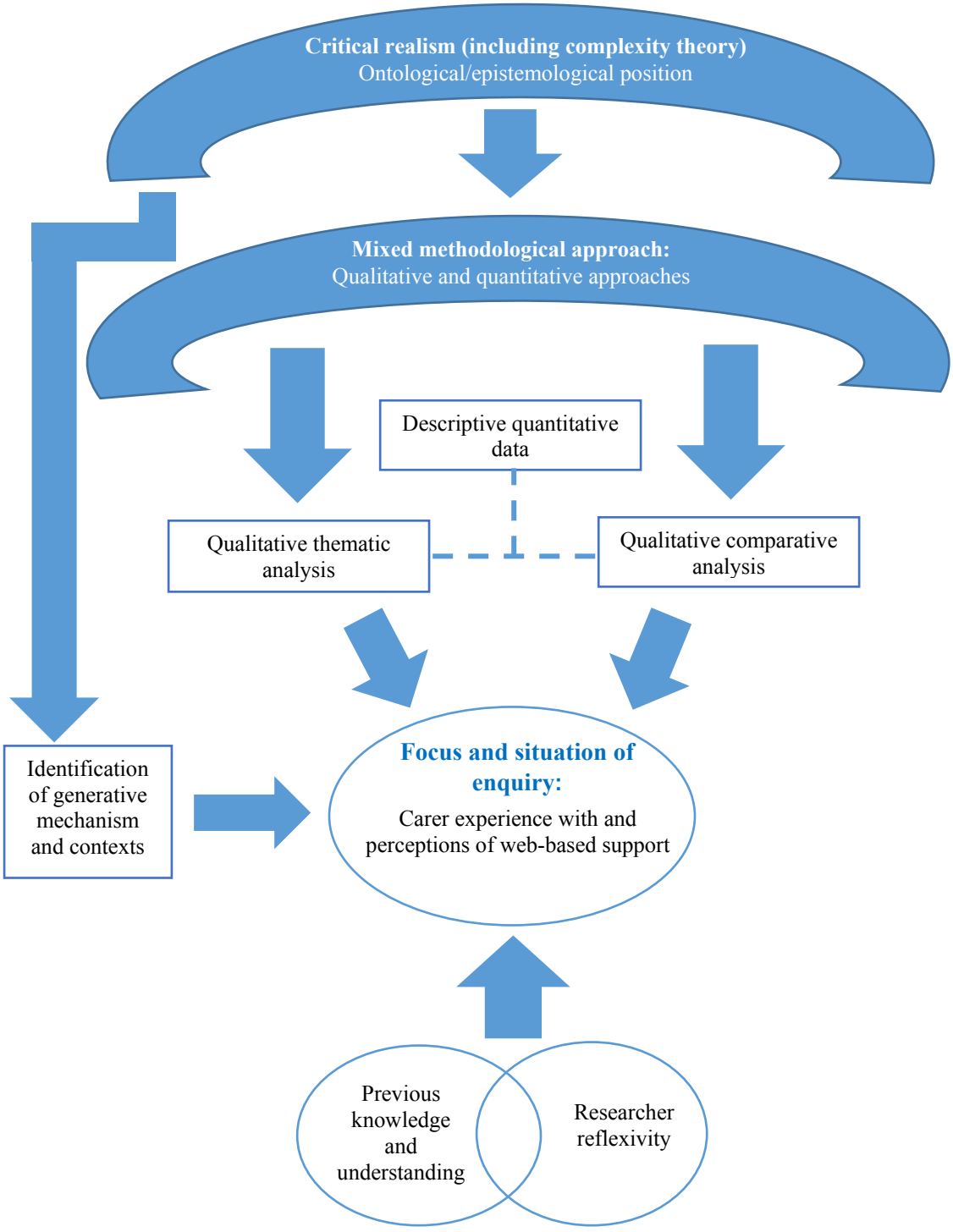

Figure 3.2. The conceptual framework underpinning the research informing this thesis.

3.2.3 Summary

The initial section of the research design and approach chapter has presented the conceptual framework underpinning this thesis. This chapter began by identifying the

importance of a conceptual framework in the research progress before presenting the three components: personal interests of the researcher, previous literature, and theoretical framework. The personal interests of the researcher have been identified based on previous experience and the longstanding interest in mental health. Review of the previous literature has highlighted carers' needs for support, difficulty accessing non-web-based support and, therefore, the possible usefulness of web-based resources.

The theoretical framework underpinning this thesis has been identified as critical realism. The alignment between critical realism and a mixed methodological approach has been briefly considered and will be expanded upon within the next section.

3.3 Design and Method

Having presented the conceptual framework underlying this thesis, the following sections will detail the methods and analysis used. This will begin by outlining the mixed methodological approach before considering QCA and thematic analysis. Issues regarding the sample and participant recruitment are addressed before turning to potential ethical concerns.

3.3.1 Mixed methods

Before presenting mixed methods as a methodology, this section will begin by clarifying quantitative and qualitative approaches to research. Similar to ontological perspectives, these methods are often depicted as existing on separate ends of a continuum. A qualitative methodology is aligned with an interpretivist perspective and adheres to an inductive approach; establishing a conclusion based from analysis of multiple statements (Blaikie, 2007). Thus, qualitative research has been praised for the ability to identify previously unidentified knowledge whilst allowing the exploration of associated properties (Klassen et al., 2012). In contrast, quantitative approaches are linked to an empiricist perspective and associated with a deductive approach; the transition from a universal statement to create a conclusion from single statements.

There are a number of differences separating qualitative and quantitative approaches, such as theoretical frameworks, researcher involvement, and perception of quality. The use of theoretical frameworks or paradigms in research has previously been highlighted

in this chapter and will not be reiterated here. Researchers have noted paradigms as influencing research questions, the choice of methods selected, and the interpretation of data (Braun and Clarke, 2006; 2013; Crotty, 1998; Guba and Lincoln, 2018). Despite this, theoretical frameworks appear to be largely used within qualitative research and are rarely considered with quantitative approaches (Mertens, 2010). One explanation for this could relate to the situational position of the researcher within the research project. Quantitative research advocates researcher objectivity to the conduction and analysis of research, perceiving this as quality assurance. In contrast, qualitative approaches accept and, in some instances, value researcher involvement in the conduction of research and analysis (Winter, 2000). Others, meanwhile, have argued that it is impossible to completely remove the researcher from the process, as this is involved in the identification of the research topics and methods of exploring this (Mertens, 2010).

Regarding the quality of research, quantitative methods are often rated highly in the hierarchy of evidence (Evans, 2003; Glasziou, Vanderbroucke and Chalmers, 2004). This is significant due to the influence of this hierarchy on clinical guidelines such as those provided by NICE. Petticrew and Roberts (2003) noted that the hierarchy proposes a fixed state of methodological soundness, placing systematic reviews and RCTs on higher tiers whilst assigning qualitative research (such as observations) to lower levels. These authors suggested that hierarchies should adapt ratings in accordance to the proposed research question; for example, for some projects, a qualitative approach is appropriate and this does not dictate lower quality. On a conceptual level, neither qualitative nor quantitative methods are superior. Both provide valuable data, however both have limitations. The majority of researchers appear to align with one approach (otherwise known as purists), which could result in a limited focus (Guba and Lincoln, 2018; Onwuegbuzie and Leech, 2005). This could fail to acknowledge the complexity of the research topic being investigated and could provide a partial explanation, compared to the use of multiple approaches.

A mixed methodological approach has been defined as the intentional use of different methods for data collection, promoting methodological fortes and reducing shortcomings, to answer research questions and understand complex phenomena (Greene and Caracelli, 1997; Klassen et al., 2012). While this can be the use of different elements of the same approach (for example, qualitative observations and interviews), mixed methods appears to be largely associated with the incorporation of qualitative and quantitative approaches. Some researchers raised concerns regarding the ability to combine multiple approaches

due to the fundamental differences defined as the incompatibility thesis (Bryman, 2006; Teddle and Tashakkori, 2009). Regarding this critique, Bazeley (2018) argued that research projects were rarely solely quantitative or qualitative. For instance, a qualitative study could incorporate some collection of demographic information such as the participant's age or gender. In contrast, a quantitative health questionnaire is likely to have been developed following focus groups with individuals experiencing that health concern. Similarly, Onwuegbuzie and Leech (2005) noted several similarities between qualitative and quantitative approaches; for instance, the development of a research question and the completion of data collection. An additional example includes condensing data prior to analysis, such as coding for qualitative interviews and the calculation of central tendencies for questionnaires.

Advantages of using a mixed method approach include an increased understanding of the research topic that qualitative and quantitative methods cannot singularly provide (Greene and Caraceli, 1997). For instance, Bazeley (2018) suggested that using a mixed methods approach in intervention studies could provide the ability to access the impact whilst also providing an understanding as to how this occurred. This understanding can be further enhanced by the use of triangulation; a technique that coalesces multiple theories, data sources or methods to investigate an outcome to develop a comprehensive explanation of the data whilst also reducing bias (Yin, 2012). From a critical realist perspective, the quantitative element of the research informing this thesis provides an indication of the impact of web-based resource use on carer emotional health. The qualitative component could assist in the identification of generative mechanisms and the contexts in which these occur.

It is important to note the disadvantages of the application of mixed methods in research. Creswell and Plano Clark (2011) proposed three key detriments to this approach consisting of researcher's skills, resources (including time), and the negative perception of mixed methods. Based from the assumption that mixed methods consists of both qualitative and quantitative components, these authors noted the requirement for researchers to be proficient in both of these methods or the need for a research team. In addressing this issue, the primary researcher has prior experience of conducting quantitative and qualitative research from previous qualifications, one of which focused on research methods. Although this disadvantage regarding the time and resources of different types of data collection and analysis was noted, the researcher accepted this due to the ability to develop a deeper understanding of the topic. Finally, the concern

regarding the ontological or philosophical position of mixed methods has previously been considered in this chapter and will not be repeated here. However, this can be rectified by the underpinning approach of critical realism.

Having previously cogitated the link between critical realism and complexity theory, this chapter will now focus on the alignment of these approaches with mixed methods. Unlike other ontological positions, there is no methodology aligned to critical realism, resulting in authors affiliating this with a mixed method approach (Braun and Clarke, 2013). Mixed methods could align to a critical realist perspective by allowing the identification of casual mechanisms underpinning a change in health. Bazeley (2018) noted that the application of mixed methods allows researchers to "ask complex questions and engage with complex, real-world environment in a socially responsive and responsible way" (p4) using multiple approaches. Therefore, this could be seen to support complexity theory by incorporating multiple approaches to fully investigate the complexity of the phenomenon of interest.

The research informing this thesis comprised of a convergent parallel design consisting of quantitative and qualitative data collection being completed simultaneously before being integrated during the analysis and discussion (Creswell and Plano Clark, 2011). Although Creswell and Plano Clark suggest that this mixed methodological design places equal weighting on qualitative and quantitative approaches, this was not achievable due to the difficulties in recruitment. In particular, this consisted of what Creswell and Plano Clark referred to as a parallel-databases variant where two strands of data are collected independently before being merged for analysis. This design was selected to develop a complete understanding of the topic whilst promoting efficiency and allowing the collection of multiple data simultaneously.

3.3.2 Qualitative comparative analysis

Schneider and Wagemann (2012) defined QCA as a methodological tool that differs from alternative set-theoretical approaches by aiming to provide a casual interpretation and incorporating the use of truth tables to facilitate analysis of causal complexity. QCA is a comparative analysis that uses Boolean terminology to determine the causal conditions relating to an outcome (Rihoux and Lobe, 2009). Comparative analyses aim to explore similarities and differences across multiple cases that can influence or impede an outcome (Ragin, 1994). This analysis differs from valuable-based research, for example linear

modelling or regression, by focusing on individual cases as opposed to patterns across the entire data set (Ragin, 1999; Byrne, 2009).

Ragin (1999) defined comparative analysis as providing "a configurational view of cases" (p1225), where cases are allocated set memberships. Set memberships determine whether cases could be designated to the concept of interest (Schneider and Wagemann, 2012). The use of set memberships defined the key difference between the two most commonly used types of QCA; crispset (csQCA) and fuzzyset (fsQCA). csQCA calibrates conditions as either belonging in a set or not achieving membership. For example, when registering web-based support use, a carer could be allocated to 1 (i.e. uses web-based resources) or 0 (i.e. no usage). Schneider and Wagemann queried the ability to allocate complex social conditions to a binary form and highlighted the importance of determining the threshold of cases that would establish the positioning of the case in set membership. Further criticism could be the possibility of reducing the complexity between cases by allocating scores that may differ to the same set membership. For instance, a carer who reported using one web-based resource could be allocated to the same condition as another who may have noted multiple uses of different resources.

fsQCA overcomes some of these critiques by allowing cases to be allocated partial membership to preserve the complexity of the focus of inquiry. A score of 0.5 is referred to as the "point of indifference". Schneider and Wagemann (2012) noted the importance of clarifying the term fuzzy, linking this to the fuzziness of conceptual boundaries (such as set membership or no set membership) as opposed to measurement. With reference to the previous example of carer online support use, the continuum would remain between 0 (i.e. no access of web-based resources) and 1 (i.e. access of web-based resources). The key difference would be that carers are allocated set-membership between these two points. Thus, this would recognise the difference between a carer who had reported usage of one web-based resource and another who had regularly accessed these resources.

QCA has been praised for providing an enhanced understanding of individual cases. However, this also advocates the importance of familiarity with all cases. As a result, authors have recommended use with small to intermediate sample sizes such as 5 to 30 cases. Whilst this could be suitable for larger samples, it could reduce the ability for familiarity with each case (Rihoux and Lobe, 2009; Befani, 2013).

Byrne (2013b) argued that comparative methods (including QCA) complement a critical realist perspective and complexity theory. He proposed that cases exist independently of

human interpretation and are complex open systems. Thus, Byrne advocated that appropriate methodology was necessary for investigating complex causality and suggested that this could be achieved by using comparative methods, in particular fsQCA. This view was supported by Befani (2013), who highlighted the difficulty in preserving the complexity of the casual conditions and the ability to generalise from results. Befani concluded that QCA could overcome this dilemma. Additionally, casual conditions are considered complex due to the ability for multiple interactions and combinations to produce or inhibit an effect (Byrne, 2013a). Thus, QCA can provide information regarding cases that did not directly cause the measured outcome. Byrne argued that it is important to consider these and to explore the differences with other casual conditions.

3.3.3 Thematic analysis

Initially, researchers reported confusion with thematic analysis and this was often incorporated or used interchangeably with other analyses (Terry et al., 2017). Attempting to resolve this confusion, Braun and Clarke (2006) defined thematic analysis as "a method for identifying, analysing and reporting patterns (themes) within data" (p79). These authors presented a systematic framework for conducting thematic analysis consisting of six stages, including familiarisation, coding and theme development. This framework will be described in further detail in the intended data analysis section.

Thematic analysis has been praised for flexibility that allows adaption to specific research projects (Braun and Clarke, 2006; 2014). These authors also acknowledged that thematic analysis can provide a valuable insight into views of different participants and allow identification of similarities and differences. However, Braun and Clarke noted that there were concerns regarding the validity of thematic analysis as an approach, remarking that this could be perceived as descriptive. Responding to these concerns, the authors claimed that this was often due to lack of understanding of the analysis. Braun and Clarke (2006) provided a systematic framework for conducting thematic analysis, however they also noted that the interpretation of data is dependent on the researcher. Nowell et al. (2017) supported this, reporting that whilst the flexibility of thematic analysis can be a strength, this can also result in variation in usage. These authors also noted that the lack of literature relating to thematic analysis compared to other approaches, such as grounded theory.

Similar to critical realism, thematic analysis is not underpinned by a philosophical approach, such as grounded theory (Braun and Clarke, 2006). Therefore, this analysis can

be linked with many philosophical standpoints and is therefore suitable for use with a critical realist perspective in identifying generative mechanisms. Despite this, Braun and Clarke highlight the importance of elaborating the researcher's philosophical perspective as these influence the themes from the resulting analysis. In this, they state that researchers develop the themes; they are not waiting to be discovered. This can be aligned with a critical realist perspective by allowing the identification of causal mechanisms or contexts that could result in an outcome.

3.3.4 Sampling issues

The research informing this thesis recruited adult carers (aged 18 years and above) or family members of an individual diagnosed with schizophrenia or psychosis. To participate, carers were required to regularly provide support to their relative; there was no timescale for the length of the caring role as web-based support is continually available. Professionals were invited to participate if they regularly worked with carers of an individual with an SMI for a minimum of 6 months; this was selected as a suitable amount of time to gain familiarity with a new role and to develop an understanding of carer needs.

Eleven carers participated in this thesis, however three withdrew due to the care recipient experiencing a relapse, were lost to follow-up or had difficulty using the web-based diary. This resulted in a sample size of 8 carers originating across the UK, 6 females and 2 males, aged between 53 and 75 years old (mean= 62.38, SD= 8.40). The female participants had a mean age of 59.17 (SD= 6.77), while the male participants had a mean age of 72 (SD= 4.24). Two carers reported that they were receiving support to assist them in managing their caring role; this consisted of a mental health charity, carer association and contact with their relative's care co-ordinator. Four carers stated using the internet to access support, and this consisted of a mental health charity website, a carer forum, running an informal support group through social media, and searching for general information via search engines. Further demographic information for carers and care recipients is displayed in table 3.1.

Table 3.1 The demographic information of carers participating in this study (n=8)

Carer	**Age**	
	Range	**53-75**
	Mean (SD)	**62.38 (8.40)**
	Gender	
	Female	6
	Male	2
	Ethnicity	
	White British	5
	British	1
	Armenian/Turkish	1
	African Caribbean/White	1
	Education	
	Higher	8
	Occupation	
	Employed	3
	Self employed	2
	Retired	2
	Other	1
	Living arrangements	
	Others (including the care recipient)	5
	Others (not including the care recipient)	2
	Not stated	1
	Relationship to the care recipient	
	Parent	6
	Spouse	2
	Length of caring role	
	2-5 years	1
	10-20 years	6
	Over 20 years	1
	Hours spent caring per week	
	5-10 hours	3
	10-15 hours	1
	15-20 hours	2
	30+ hours	2
	Receiving support for caring role	
	Yes	2
	No	6
	Use internet for support	
	Yes	4
	No	4
The Care Recipient	**Age**	
	Range	28-54
	Mean (SD)	37 (8.59)
	Diagnosis	
	Schizophrenia or psychosis	4
	Unspecified	2
	Schizoaffective Disorder	1
	Severe Depression (with psychosis)	1
	Health (at baseline)	
	Quite well	2
	Not very well	4
	Not at all well	2

Seven professionals were recruited for this thesis, however one participant was excluded due to the failure of the recording device and inability to schedule another interview. This resulted in 6 participants (mean age= 46.50, SD= 13.32) aged between 31 and 64 years old (see table 3.2 for further demographic information). Of these three were male (mean age= 45.67, SD= 13.01) and three were female (mean age = 47.33, SD= 16.50). As with carers, the professionals originated from across the UK, with two working in healthcare and four working in the voluntary sector.

There was no incentive for participating in this study and data collection was concluded following time constraints. No participant requested that the data they provided be removed from analysis.

Table 3.2. The demographic information for professionals participating in this thesis (n=6).

Professional	**Age**	
	Range	31-64
	Mean (SD)	46.50 (13.32)
	Sex	
	Female	3
	Male	3
	Ethnicity	
	White British	5
	Other	1
	Occupation	
	Mental health or carer charity/organisation	4
	Healthcare	2
	Education	
	Higher	6
	Recommend internet for support	
	Yes	5
	No	1

Participants were recruited by a range of approaches consisting of; information sharing seminars, Twitter, Instagram, Facebook, Citizen Science, carer and mental health groups/charities/organisations and Google Ads. Healthcare professionals who regularly worked with carers were also recruited from NHS Trust. See table 3.3 for an overview regarding carer recruitment methods. Recruitment documents are included in appendix two.

Table 3.3. A table of the recruitment methods utilised in the research informing this thesis.

Strategy	Description
Social Media	<u>Facebook</u> A Facebook account was created to contact web-based support groups created by charities/organisations or other carers. These groups were identified by searching for relevant terms, for instance carers, carer schizophrenia, etc. Admins were contacted through the Facebook private messaging system to seek permission to post information about the study, inclusion criteria and contact details. Those interested in taking part in the study were asked to contact the researcher and not to comment on the post to preserve participant confidentiality. If individuals did reply to the post, the researcher messaged them privately, thanking them for their response and to contact them directly via email as this was a more secure method of contact. <u>Twitter and Instagram</u> Carers were also recruited through social media; this utilised a professional Twitter account to post tweets regarding recruitment and created an Instagram account for this purpose. Messages were posted at various days and times over a 4-month period (April to August 2017), with a total of 17 from the researcher's Twitter account and three tweeted to an organisation. Both Instagram and Twitter messages comprised of an image detailing information regarding the project to portray content in an accessible way to users within the character constraints. The tweet or post contained the same message: "I'm looking for #carers or #caregivers of people with (other hashtags here) to take part in some research, see pic for more info". Hastags comprised of #mentalhealth, #severementalillness, #schizophrenia, #psychosis, #bipolar, and #personalitydisorder, which were used interchangeably. Interested parties were asked to contact the researcher directly for further information.
Information Sharing Seminars	Six information-sharing seminars were held at North East carer or mental health charities and organisations at different times of the day to accommodate carers. Seminar materials consisted of a PowerPoint presentation and an information booklet including information regarding web-based resources for carers of an individual with schizophrenia or psychosis (see appendix two). These included sections regarding previous research into online interventions, available

Table 3.3 continued:

	web-based support such as FutureLearn, information about mobile phone apps, and concluding with a brief quality assessment of web-based resources. At the end of the seminars, attendees were provided the information brief and were invited to participate in the study. Attendees were also asked to complete an evaluation form to guide future seminars and for the researcher's personal development.
Carer and mental health charities and organisations	UK-based carer and mental health charities, groups and organisations were contacted and sent information regarding the study. If consented, they were asked to distribute the information to carers and professionals in their organisation. Healthcare professionals were recruited through NHS channels; managers were asked to distribute this to members of staff, who, if interested, were asked to contact the researcher directly.
Citizen Science	Citizen Science (no date) is an organisation partnered with the NHS that advertises research studies to patients and healthy volunteers, whilst promoting patient and public involvement. Permission was obtained to advertise the project on the website and this was also included in monthly newsletters and social media platforms. The webpage provided the title of the study above a general image, a brief summary stating participation inclusion criteria and what the study involved, and the opportunity to download the information brief. Potential participants were asked to complete the web-based form to express interest.
Google Ads	The study was advertised via Google Ads resulting in the advertisement appearing following the searching of specified keywords. The keywords consisted of 'family psychosis', 'carer online support', 'carer personality disorder', 'family bipolar', 'carer psychosis', 'family mental illness', 'carer bipolar', 'carer depression', 'family depression', 'family schizophrenia', 'carer', 'family personality disorder', 'carer mental illness' and 'carer schizophrenia'. To the viewer, this displayed the study title as a link and a very brief description stating that this was a research project focusing on online support. Clicking on the link would direct the user to a blog page containing the study information brief. Again, those interested in participating were asked to contact the researcher directly.

Originally, there was an aim to recruit a minimum of 25 carers, however difficulties in recruitment resulted in a small sample. Suggestions for this include other UK research projects investigating a web-based intervention that was recruiting carers of an individual with schizophrenia or psychosis. However, Sin, Henderson and Spain (2016b) noted the difficulty recruiting siblings of an individual with psychosis to a health-based intervention from early intervention in psychosis services. They found that barriers included organisational factors such as passing information being perceived as an additional workload or selective selection of individuals. With regard to carer-related factors, it was suggested that reluctance to participate in research could be due to concerns over their relative's reaction.

3.3.5 Data collection

Data collection relates to the approaches outlined above. Once agreeing to participate in the research study, carers were asked to complete a weekly diary measuring web-based support use and views regarding these resources for a total of six weeks. The weekly diary provided a list of web-based resources, however this also allowed carers to note support accessed that may not have previously been considered. Carers who attended the information-sharing seminars also had the provided booklet which provided a list of resources and instructions relating to access. Carers were also invited to complete three questionnaires assessing wellbeing and QoL at baseline and 6-weeks follow-up before being asked to attend a face-to-face, phone or Skype individual interview. Professionals were invited to attend an individual interview. Incorporating questionnaires and individual interviews into a mixed methodological approach allowed the ability to develop a deeper understanding regarding the role of web-based resources in promoting carer wellbeing. Study materials are included in appendix three for further consideration.

3.3.5.1 Weekly diaries

Elliott (1997) defined a research-driven diary as a structured log of health-based behaviour, noting that this could be a valuable option when observation is not appropriate or feasible. The use of diary-based methods as a source of data collection has been praised for allowing a precise approximation of participant behaviour, for instance in relation to the access of web-based resources (Bryman, 2016). Wyness, Douglas and Teijlingen (2004) noted that diaries are a discreet method of data collection and valuable for

triangulation. However, they also state the importance of motivating users to complete these. There are notable disadvantages in using diaries for data collection, including for instance; increased risk of attrition, reduction in quality of submitted data, and the failure of immediate recording of details that could later be affected by memory fatigue (Bryman; Wyness et al.).

Carers were asked to complete a weekly diary monitoring web-based support use which was available online and offline. The paper diary was an 18-page booklet separated into 6 sections for each week (see appendix three), and included a question regarding whether web-based resources had been accessed and, if not, carers were instructed to move onto the following week. Otherwise, participants were asked to select the resources accessed from a predetermined list. However there was the opportunity to record other forms of support that were not included.

The web-based version was accessed via Bristol Online Survey (see appendix three), now known as Online Surveys (no date). The web-based diary included questions about web-based resources, for example the Carer Trust and Mind. Each section included questions regarding access, time spent on resources, views and further comments. As with the paper diary, there was an opportunity to note support not previously included. Participants who selected to not use web-based resources were directed to a feedback page that focused on the usefulness, usage, opinions, suggested improvements and other comments regarding the diary.

3.3.5.2 Questionnaires

A key advantage of this approach is the ability to generalise results of a sample to the population and also indicate change following the implementation of an intervention (Bryman, 2016; Winter, 2000). However, an underlying assumption of the application of quantitative questionnaires is the ability to measure unobservable concepts. The ability of a questionnaire in measuring a concept is considered in terms of construct validity. Construct validity is defined as the ability for the questionnaire to reflect the area of interest (Creswell and Plano Clark, 2011; Zachariadis, Scott and Barret, 2013). However, Boyle (1993) discussed the complexity of assessing unobservable variables. Referring to mental illness, no-one can directly observe schizophrenia but the existence of this is assumed by attributing observable variables to a theoretical concept. For instance, the identification of positive and negative symptoms. Thus questionnaires are based in a

theoretical construct of schizophrenia based on previous literature and reported experiences, which could change over time with increased understanding.

The use of questionnaires also assumes that participants will have similar understanding of the research questions as the questionnaire developer (Feilzer, 2010). Feilzer goes on to note that participants may select similar answers but for different reasons; thus, without the inclusion of a qualitative element, this data would be lost. This thesis attempted to overcome this concern by using a mixed methodological approach to allow carers to provide further information regarding their perception of the use of web-based resources on their health.

Three questionnaires were administered to carers at baseline and at 6-week follow-up to assess wellbeing and quality of life following web-based support use. This timescale was selected as appropriate to observe potential fluctuations in carer health. Additionally, this provided a pragmatic timeframe for the research project whilst also providing a manageable period for research participants, therefore reducing the risk of attrition. The questionnaires used in the research informing this thesis are as follows:

Warwick-Edinburgh Wellbeing Scale (WEMWBS) assessed the hedonic and eudemonic aspects of mental wellbeing, comprising of subjective wellbeing and psychological functioning (Stewart-Brown and Janmohamed, 2008). This is a 14-item scale rated on a 5-point Likert scale, ranging from 'none of the time' to 'all of the time'. Examples of questions include "I've been dealing with problems well" and "I've been feeling loved". The total score (from 14 to 70) is calculated by adding the individual scores; a higher score indicating higher level of wellbeing. There is no cut-off score that indicates poor wellbeing with suggestions that results should be depicted as a mean score and compared to the population mean of 51. WEMWBS was selected due to findings of good content validity, achieving reliability scores ranging from 0.83 to 0.91 (Stewart-Brown et al., 2009; Tennant *et al.,* 2007). Permission for use was obtained from the web-based registration website (See appendix three).

Hospital Anxiety and Depression Scale (HADS) consists of 14 statements, 7 for anxiety and 7 for depression, rated on a 4-point Likert scale (ranging from 0 to 3) relating to how the respondent has felt in the past week. Example questions include "I get sudden feelings of panic" (anxiety) and "I can laugh and see the funny side of things" (depression). Total score is calculated by addition of score, resulting in a total score for depression and anxiety, or can be combined to create a total score of distress. Scores higher than X on

either subscale indicate severe distress. HADS has been previously used in studies involving carers of people with schizophrenia or psychosis (e.g. Fortune et al., 2005).

Adult Carer Quality of Life Scale (AC_QoL) is a free questionnaire developed following consideration of previous literature and in collaboration with carers (Elwick et al., 2010). This consists of 40-items with eight 5-item subscales: Support for Caring, Caring Choice, Caring Stress, Money Matters, Personal Growth, Sense of Value, Ability to Care, and Carer Satisfaction. Example questions include "I have a good level of caring support" and "I feel depressed due to caring" and responses are scored on a 4-point Likert scale ranging from 'never' to 'always', with 14 items reverse scored. Higher scores indicate greater level of quality of life with a total below 40 (or subscale below 5) indicating some caring difficulties (Joseph et al., 2012). The AC_QoL scale can be administered for single use or pre- and post-test to assess the impact of an intervention, has been used in previous research with carers, and has been reported to have a Cronbach Alpha score of .77 and .93 (Brand, Barry and Gallagher, 2016; Hallam and Morris, 2014). Permission for use was obtained from the creators of AC_QoL (see appendix three).

3.3.5.3 Qualitative interviews

Individual interviews provide the ability to explore participant views, experiences and beliefs and are one of the most commonly-reported methods for collecting qualitative data (Braun and Clarke, 2013). Interviews also allow the uncovering of previously-unidentified aspects (Klassen et al., 2012). Semi-structured interviews have been praised for providing the benefits of a structured interview, while also including the flexibility to explore topics previously unconsidered. Therefore, this method was selected to explore the views of carers and professionals regarding web-based resources. Participants were invited to attend a semi-structured interview that was completed face-to-face, or via Skype, telephone or email.

Technology has facilitated the conduction of qualitative data collection, for instance phone, Skype and email interviews have increased access to participants without the need to travel. However, this could create difficulty establishing rapport and the inability to identify visual cues that could interpret natural pauses. Bryman (2016) also noted that telephone interviews are more likely to be shorter than face-to-face interviews. However, as individuals with schizophrenia can experience relapse, the support required from carers may fluctuate, therefore causing difficulty in travelling to locations or allocating time.

Technology provided a greater availability to carers by promoting a time and method convenient to them. Additionally, this provided the ability to recruit from throughout the UK due to difficulty recruiting. Whilst the use of Skype could overcome the difficulty in identifying facial expressions via telephone interviews, it was important that both options were available to ensure that individuals with a range of technological literacy could participate in the study.

Carers and professionals were interviewed to triangulate views towards the use and construction of web-based resources. As previously noted, triangulation has been defined as a technique to compare data sources or viewpoints to enrich and increase understanding or explain phenomenon, and is perceived as a method to reduce bias and increase credibility of results (Barusch et al., 2011; Yin, 2014). If sources provide complimentary responses, triangulation is considered to be successful (Yin, 2012). By interviewing carers and professionals, the research informing this thesis aimed to include carers' subjective experiences of caring for their relative and professional expertise of supporting family members, and therefore develop a more in-depth understanding of web-based support usage and mechanisms for developing a web-based intervention. An overview of participants and type of interview conducted is presented in Table 3.4.

Face-to-face interviews were held at carer or mental health organisations/charities or at Northumbria University. Contact details were obtained from participants who requested telephone and Skype interviews. Interviews were audio recorded and uploaded to a password-protected computer before being deleted from the device. There were three topic guides for the interviews; carers who used web-based resources, carers who didn't use this form of support, and professionals who regularly worked with carers (see appendix three). For carers who used web-based resources and professionals, interviews focused on web-based support use, views of web-based resources, possible difficulties in access and the possible impact on carer wellbeing and QoL. Relating to interviews with carers who did not use web-based resources, interviews focused on barriers preventing usage and suggestions on overcoming these. All interviews included questions focusing on recommendations for a framework for a web-based resource and possible barriers that should be considered.

Table 3.4. A table detailing the participants and type of interview.

Participant Pseudo name	**Participant**	**Age**	**Information**	**Method of Data**	**Interview Type**
Lynn	Carer	71	Lynn is caring for her 37-year-old son who was diagnosed with schizophrenia.	Interview and Diary	Skype
Penny	Carer	63	Penny is caring for her 30-year-old son/daughter who was diagnosed with schizophrenia.	Interview and Diary	Phone
Rosa	Carer	57	Rosa is caring for her 35-year-old son who was diagnosed with schizophrenia.	Interview and Diary	Phone
Maria	Carer	51	Maria is caring for her 54-year-old husband who was diagnosed with psychotic depression.	Interview and Diary	Face-to-Face
Eddie	Carer	69	Eddie is caring for his 35-year-old son who was diagnosed with schizophrenia.	Interview and Diary	Phone
Brian	Carer	75	Brian is caring for his spouse who was diagnosed with schizoaffective disorder.	Interview	Email
Stella	Carer	54	Stella is caring for her 28-year-old son/daughter.	Interview and Diary	Phone
Heather	Carer	57	Heather is caring for her 32-year-old son/daughter.	Interview	Face-to-Face
Lee	Professional	33	Lee is working in the NHS. He notes his duties as getting to know carers, promoting hope and developing a recovery-focused approach.	Interview	Skype/Phone

Table 3.4 continued:

Robert	Professional	59	Robert works in the NHS providing medical support and support navigating the NHS system. He reports working closely with carers of individuals with an SMI or Alzheimer's disease.	Interview	Phone
Linda	Professional	64	Linda is working in a third sector charitable organisation that supports carers of an individual with a mental illness. She runs carer support groups and courses while also providing one-to-one support.	Interview	Phone
Chloe	Professional	31	Chloe works in a charitable organisation that supports carers of an individual with a mental illness. Her role entails supporting carers and directing them to relevant information and services.	Interview	Skype
Jim	Professional	45	Jim works in a charitable organisation, whilst this does not provide support specific to carers, a carers attend this organisation and Jim has close connections with local carer organisations. He provides signposting, advice and creates sessions within his role.	Interview	Face-to-Face
Ella	Professional	47	Ella works in a charitable organisation that supports carers of an individual with a mental illness. Her role entails providing emotional and practical support to carers.	Interview	Phone

3.3.6 Intended data analysis

The following section will present the data analysis of weekly diaries, questionnaires and interviews in accordance with the mixed methodological approach and the ontological perspectives underlining this thesis.

Weekly diaries and questionnaires

Quantitative data obtained from carer weekly diaries and questionnaires were analysed using dynamic pattern synthesis (DPS) (Haynes, 2018); an analysis designed for use with small samples. DPS incorporates cluster analysis and QCA to determine causal conditions that relate to outcomes identified via clusters. Therefore, causal conditions were calibrated to set membership in accordance to QCA guidance. Conditions were allocated to csp-set conditions due to the small sample size. For information regarding calibration and QCA, see appendix four.

Haynes (2018) proposed the use of SPSS to identify clusters for DPS analysis. The research informing this thesis used the positive and negative difference in psychometric scores following 6-week use of web-based resources as predetermined clusters. The causal conditions indicative of an outcome (i.e. a change in psychometric scores) are displayed in truth tables. Truth tables are used to demonstrate similarities and differences between cases, with each row representing each potential combination relating to the outcome (Ragin, 1994). Solutions were determined by demonstrating what casual conditions were required to trigger the outcome, with any differences between conditions being acknowledged and discarded.

Qualitative comments from the weekly diaries were incorporated into the thematic analysis, as outlined below.

Qualitative Interviews

Carer and professional interviews were analysed using the framework for thematic analysis developed by Braun and Clarke (2006). This analysis consists of six-stages;

1. Familiarisation with dataset – achieved by transcribing, reading and noting initial thoughts of the interviews.
2. Code generation - codes are generated whilst collecting relating quotes.

3. Theme identification - codes are grouped into themes.
4. Review - ensuring that themes represent the codes and are apparent across the dataset.
5. Definition and naming - themes are refined and given clear definitions and names.
6. Report production - final analysis, selection of quotes and the generation of the report.

Firstly, recordings were transcribed and reviewed by the researcher to facilitate immersion with the data. The following stage consisted of the development of initial codes, which were then were reviewed and those noted as similar were merged, before being merged into themes. Identified themes were reviewed before being defined and named. See appendix four for an overview of analysis.

Carer and professional interviews were analysed as one data set. The merit in separately analysing carers and professional interviews was initially considered; for instance, providing a clear differentiation between both parties' views. However, the research question did not state a comparison between carer and professional views and was more concerned with the needs of carers of an individual with an SMI (see 1.3 Research aims and questions). Additionally, following initial analysis, it was evident that similar themes were identified from both data sets, resulting in the decision to merge both. To ensure differences between carer and professional perspectives were acknowledged, this is directly discussed within presentation of the thematic analysis presented in Chapter 4.

3.3.7 Ethical issues

Approval for this study was obtained from Northumbria University Health and Life Sciences Ethics committee (see appendix one). As this project focused on carers and not patients with schizophrenia, IRAS and HRA approval was not required. Throughout the course of this thesis, four ethical amendments were submitted to approve the information-sharing seminar materials, the introduction of the weekly diary and completing interviews through Skype and telephone to accommodate carers. One amendment expanded the participant criteria to carers of an individual with schizophrenia, psychosis, bipolar disorder, severe depression and personality disorders. However, the final sample included carers of an individual with schizophrenia or psychosis. Finally, this research study was

reviewed by NHS Ethics Committee to recruit NHS staff who regularly worked with carers of an individual with an SMI.

Ethical considerations included preservation of confidentiality and possible distress occurring following participating in this study. Regarding confidentiality, participants were reassured that data provided about themselves or the person they were caring for would be anonymous. Participants were allocated a participation number and personal information and data collected were separated and securely stored. During the interviews, it was possible that participants could have over disclosed information about themselves or those who they cared for. If this had occurred, participants would have been reminded of over disclosure and any personally-identifiable information would have been censored in the transcription process.

As carers could be under stress due to the caring role, a further ethical implication could be the risk of distress with participation in this study. If a carer had received a high score on HADS, indicating severe anxiety and depression, they were directed to their local carer organisation, general practitioner (GP) or improving access to psychological therapies (IAPT) services for further support. If carers appeared distressed during the process of this thesis or stated a need for further information or support, they were also directed to these resources.

No participant withdrew from the study on ethical grounds; reasons for withdrawal were discussed earlier in this chapter. There were no ethical dilemmas or issues encountered in this thesis.

3.4 Chapter summary

This chapter began by highlighting the importance of a conceptual framework in research before presenting this in relation to this study. In doing so, this chapter has offered critical realism as the ontological perspective underpinning this thesis whilst revisiting the relevant literature and reflexivity of the researcher. Critical realism proposes the existence of a stratified reality comprised of empirical, actual and real levels. The real level highlights the importance of identifying generative mechanisms and contexts triggering these. By doing so, this argues the value of providing an explanation of observed effects as opposed to a description.

Following this, the research design and method of data collection was outlined. This presented mixed methods as the methodology unpinning the critical realist perspective in the research informing this thesis. QCA and thematic analysis were presented as intended data analysis for the quantitative and qualitative data collected. Finally, this chapter considered sampling and ethical issues relating to the research informing this thesis.

The following chapter will present both the quantitative and qualitative findings of the research informing this thesis before moving to the presentation of the framework for a web-based supportive intervention for carers of an individual with schizophrenia or psychosis.

Chapter 4. Presentation of findings and initial discussion

4.1 Chapter overview

The purpose of this chapter is to present the key findings of the research informing this thesis. First, this will outline web-based resources reported to have been accessed by carers over the six-week period. Following this, the chapter will illustrate health questionnaire findings, highlighting difference in scores between baseline and 6-week follow-up.

The focus then moves to QCA and presents the causal conditions (originating from weekly diaries of web-based resource access) associated with a change in carer wellbeing or QoL. The second QCA will consider the influence of demographic factors and web-based support access on change in health scores. In this analysis, week three is used as the highest reported access of web-based resources.

The thematic analysis of individual interviews with carers and healthcare professionals are presented. Each theme is defined and outlined with use of direct quotes to illustrate relevance to participant situations. Following this, there is an in-depth consideration of a key element identified within the thematic analysis. An assemble analysis considering connections between the themes using one as a focus point is also presented.

Finally, in accordance to a critical realist approach, generative mechanisms and contexts are presented. Mechanisms and contexts were identified via individual interviews and QCA.

4.2 Findings from the use of diaries and questionnaires

This initial section will present the weekly diary of web-based support use before considering health questionnaires completed at baseline and 6-weeks follow-up. The following section will present the findings from the QCA.

4.2.1 Diaries

Of the eight carers participating in the research informing this thesis, six weekly diaries were included in analysis, with two diaries being excluded due to no or minimal use. Overall, 17 web-based resources were accessed over this period and are presented in Table 4.1.

As can be seen from the below table, seven of these resources were included in the initial information-sharing seminar and diary of weekly web-based resource access. The most accessed resource was a web-based forum (www.schizophrenia.com), with one carer accessing this five times a week for two weeks. Carers reported spending more time on this forum, along with YouTube and mental health/carer information websites, and reported this as 1-3 hours per session.

Table 4.1. A tabulation of web-based support reported to have been accessed in the 6-week period.

Name of Resource	**Description**
Web-based forum (www.schizophrenia.com)	This American web-based forum provides a platform for interaction between family members of an individual with schizophrenia. Carers are also able to access informational articles about schizophrenia such as identification, support and treatments. There are also articles relating to research studies. However, the participant who reported accessing this resource primarily accessed the web-based forum for family members and carers.
Carers Trust Website*	Carers Trust provides a range informational articles regarding the caring role. Examples consist of benefits and carer assessments. However, there appears to be limited information regarding mental health carers. This resource does not include a web-based forum, however it does direct carers to other resources.
Future Learn online course*	Future Learn provides free web-based courses developed by universities. This resource includes courses relating to wellbeing promotion and also a course developed for carers of individuals with schizophrenia or psychosis, which was developed by King's College London and led by an individual specialising in carer support.
The Mind Website*	Mind is an established mental health charity. This website provides a range of information on mental health and has a section for supporting an ill relative with schizophrenia, schizoaffective disorder or psychosis. This also includes a web-based forum, as outlined below.
Mind Online forum*	One participant searching for a web-based forum attempted to access this resource, however reported that it was targeted at individuals with mental illness as opposed to carers. They did not revisit this resource again.
Royal College of Psychiatrists Website*	The Royal College of Psychiatrists provides a range of information about schizophrenia. This resource also provides some content for family members, for instance information about carer assessments and available support.
Email communication with healthcare professional	Whilst this method may not be considered a traditional method of web-based support, one carer valued this communication and found this promoted collaboration in caring for her relative.

Table 4.1 continued:

Carer UK website*	Carer UK is a charitable organisation that provides information to carers. Like Carer Trust, this provides general information regarding the caring role and includes a section regarding web-based support. This website includes a forum for carers featuring a range of topics including practical advice, fun and games, and a section focusing on carers of an individual with a mental illness.
Online searches/Google searches	This refers to information searches via search engines, such as situations encountered within the caring role. The use of online searches will be further outlined in the thematic analysis.
YouTube	YouTube provides access to web-based videos that can be uploaded by individual users or organisations.
Mental Health Recovery Website	This web-based resource is the Wellness Recovery Action Plan (WRAP) website, linked to a non-web-based course, and providing a 'toolbox' to promote wellness and recovery. This includes stress reduction techniques and peer counselling. This resource also assists users in identifying relapse and creating a crisis plan.
Rethink website*	Rethink is an established mental health charity based in the UK. This website provides information regarding mental illness and also has a "Carers' hub" featuring topics such as confidentiality and planning for future care. The carer hub includes a section specifically for siblings of individuals with psychosis.
Soteria website	Soteria is a network advocating the creation of non-pharmaceutical treatment of schizophrenia. However, this website appears to be largely out-of-date with limited information.
Citizens advice website	This website provides information regarding benefits, work, family etc. The information provided is not focused on carers of individuals with psychosis, however is useful to situations likely to be encountered. For example, applying for a PIP assessment.
Insight timer	This resource appears to be a free meditation and mindfulness app available on the Google Play Store.
NICE website	The National Institute of Clinical Excellence provides national guidelines for the treatment of mental illness, including schizophrenia.

Table 4.1 continued:

www.psychcentre.com	This reported resource appeared to have been noted incorrectly. A similarly-named website is www.psychcentre.co.uk, which provides bi-lingual therapies. For instance, Mindfulness and CBT. This resource also provides informational articles.

* Included in the information-sharing seminars and noted in the diaries.

Figure 4.1 presents the amount of web-based resources accessed over the 6-week period. Resource access increased from week one to week three before decreasing. There are several explanations for this. For instance this could indicate increased confidence in using web-based resources. This could also correspond with reminders of web-based resource use and contact regarding invitations for individual interviews.

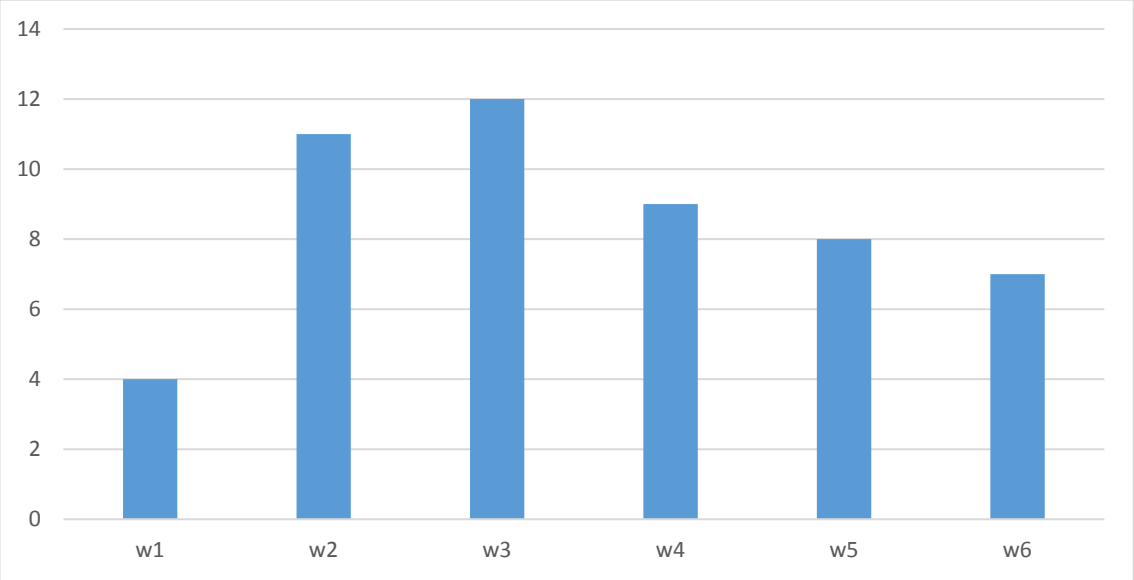

Figure 4.1. A figure demonstrating the amount of web-based support accessed by carers over a 6-week period (n=6).

4.2.2 Questionnaires

Raw data from the questionnaires was inputted into IBM SPSS Statistics 22, where the mean and standard deviations of carers were calculated at baseline and 6-weeks follow - up. Six carers were included in this section of the analysis. Due to the small sample size, significance testing was not completed. However descriptive data is presented below in Table 4.2.

Table 4.2 *The mean and standard deviations of the outcome measures at baseline and 6-weeks follow-up for carers of an individual with schizophrenia or psychosis (n=6).*

Questionnaire	Time point	Mean	Standard deviation (SD)	Comments
WEMWBS	Baseline	43.83	6.08	The change from baseline to 6-weeks follow-up suggest that there was an increase in carer wellbeing, therefore indicating an increase in emotional health.
	6 Weeks	47.50	8.19	
HADS (depression)	Baseline	6.33	1.86	These scores indicate a small increase in depression following 6 weeks web-based support use. This indicates a reduction in emotional health.
	6 Weeks	6.67	1.63	
HADS (anxiety)	Baseline	10.67	3.50	This suggests a decrease in carer anxiety following 6 weeks of web-based support use, suggesting improved emotional health.
	6 Weeks	9.17	3.76	
AC_QoL support for caring total	Baseline	4.33	2.16	The change in these scores indicate an increase in the AC_QoL subscale support for caring. Support for caring measures the level of perceived support, therefore scores suggest that carers feel they are supported to a higher extent following 6 weeks of web-based support use.
	6 Weeks	4.50	1.97	
AC_QoL caring choice total	Baseline	7.33	2.66	This suggests there was a reduction in the AC_QoL subscale caring choice, suggesting lower rating of control and ability to engage in non-caring related activities.
	6 Weeks	7.00	3.22	
AC_QoL caring stress total	Baseline	9.50	2.35	Following 6 weeks of web-based support use, there was a decrease in AC_QoL subscale caring stress indicating reduced mental and physical stress.
	6 weeks	8.17	2.32	

Table 4.2 continued:

AC_QoL money matters total	Baseline	9.00	3.63	These scores indicate an increase in money matters (AC_QoL subscale) suggesting carers were less distressed regarding their financial situation.
	6 Weeks	10.50	3.73	
AC_QoL personal growth total	Baseline	7.17	4.31	There was an increase in personal growth following 6 weeks web-based support use. This indicates that carers reported personal growth, development and positivity regarding their situation.
	6 Weeks	8.67	4.08	
AC_QoL sense of value total	Baseline	7.00	2.76	There was an increase in the AC_QoL subscale sense of value following six weeks of web-based support use indicating carers feel more valued and respected in their role.
	6 Weeks	8.33	3.88	
AC_QoL ability to care total	Baseline	8.00	3.63	The ability to care AC_QoL subscale decreased following 6 weeks of web-based support use. These scores suggest that carers had a lower ability to cope with the caring role and perceptions of competency.
	6 Weeks	7.67	2.73	
AC_QoL carer satisfaction total	Baseline	5.67	2.50	Carer satisfaction (AC_QoL subscale) increased from baseline to 6 weeks of web-based support use indicating a higher level of satisfaction with life and carer role.
	6 Weeks	6.33	2.58	
AC_QoL total	Baseline	58.00	12.31	Total quality of life increased following web-based support use. The total scores suggest that carer QoL increased from baseline to 6 weeks.
	6 Weeks	61.17	15.96	

The above table presents the quantitative results from baseline to 6 weeks, however it is useful to consider what would constitute meaningful change. The guidance for WEMWBS suggests that individual meaningful change would constitute between 3 to 8 points increase from baseline to follow-up, indicating improvement (Putz *et al.,* 2012). However this guidance does not include content regarding meaningful change at a group level. Similarly, with regards to AC_QoL scale, whilst this has been shown to be effective in assessing the impact of interventions, there does not appear to be guidance regarding clinically-significant change (Joseph *et al.,* 2012). Recommendations suggest that total scores below 40 and individual subscales below 5 indicate difficulties with QoL. Finally, the results for HADS show a reduction in depression and an increase in anxiety. The scoring guidance again focuses at an individual level, suggesting that a score under 7 is considered normal, 8-10 indicates mild anxiety or depression, 11-14 refers to moderate levels and 15-21 is severe levels.

The inability to establish group meaningful change generates difficulty in interpreting the results and in establishing whether changes can be attributed to web-based support use. Caution is thus needed in the interpretation of these results as causally indicative in themselves. However, within the context of the research study which informs this thesis, the above results provide a means of identifying candidate variables for further explorations within the qualitative element of the study.

4.2.3 Summative discussion

The above table shows an increase in carer wellbeing and QoL following 6 weeks of web-based support use. There was also a decrease in anxiety. These scores suggest that web-based resources can have a positive impact on emotional health. However, scores also showed an increase in depression, and reduced caring choice and ability to care.

Carers discussed the impact of web-based resources on their health and wellbeing during individual interviews. One carer reported that web-based resources could be beneficial for wellbeing, whilst another praised their information but noted limited effect on health. This carer described the value of web-based resources on knowledge:

> *"…feel you're getting somewhere that you've got some information or you've got some, erm, knowledge that you didn't have before…" (Stella, Carer Interview)*

Another carer praised the availability of web-based resources in providing immediate support access:

> *"…because, you know, anything else you've got to wait haven't you?" (Rosa, Interview)*

However, it is important to consider the influence of other resources that may have impacted carer health during this period:

> *"…actually I was attending a … course during the time I was doing this diary… so the two things tied in quite well…" (Penny, Interview)*

Despite this, these resources could also have associated web-based resources to promote access to information and techniques, indicating a blended approach to support provision:

> *"…the website gives more information resources etc. Very clear" (Penny, weekly diary).*

Further information regarding the impact of web-based resources identified from individual interviews with carers will be outlined later in this chapter.

Whilst these findings indicate that web-based resources can have a beneficial impact on carer mental wellbeing and QoL, these are descriptive and based from a small sample size. However, the thematic analysis could provide a detailed insight regarding the impact of web-based resources on carer health. The QCA will also highlight the causal conditions (or prime implicants) relating to change in questionnaire scores.

4.3 Qualitative comparative analysis

Having presented the key findings from the weekly diaries and questionnaires, attention will now turn to the QCA findings underpinning this thesis. The key terms associated with DPS and QCA analysis are presented in the table below.

Table 4.3. A tabulation of the key terms associated with qualitative comparative analysis (QCA).

Term/Concept	**Explanation**
Calibration of causal conditions	Calibration conditions refers to allocating causal conditions to a set membership. Although this can refer to fuzzy-set and crisp-set values, this thesis will focus on crisp-set due to the small sample size.
Dynamic pattern synthesis (DPS)	DPS is a case-based analysis proposed by Hayes (2017) that incorporates QCA with cluster analysis.
Cluster analysis	Cluster analysis aims to categorise cases into groups.
Crisp-set values (csp-set)	Crisp-set values assign causal conditions as either fitting or not belonging to a set membership, for example carers using or not using web-based support.
Tendencies	Tendencies refer to instances that were close to prime implicants, described as "near misses" (p26) by Haynes (2018).
Prime implicants	Hayes (2017) define prime implicants as instances of cases displaying the same thresholds, identified through use of rows in truth tables.

The underlying methodology for QCA and case-based analyses has been considered in the previous chapter. However, the key points of this analysis are provided below for clarity;

- QCA is a case-based analysis that investigates casual conditions influencing the phenomenon of interest by use of Boolean terminology.
- Complementary with complexity theory, QCA also acknowledges the absence of conditions required for occurrence of an outcome.
- Causal conditions are identified by use of truth tables.
- Variables of interest are calibrated into crisp-set or fuzzy-set memberships.
- DPS incorporates QCA with cluster analysis.

The outcome measures (or clusters) included within this analysis consisted of changes in carer wellbeing, QoL, anxiety and depression. These clusters are summarised in Table 4.4. and were not included in the QCA analysis due to the weighting towards one condition, indicating that this causal condition would continually occur as a relevant aspect towards the outcome.

Outcomes measures for clusters and causal conditions (otherwise referred to as prime implicants) were converted to crisp-set values (see Table 4.4, 4.5 and 4.7). The raw data utilising binary and Boolean terminology is itemised in appendix three of this thesis. Findings presented below are outlined in meaningful English to lend clarity to discussion.

Table 4.4. A presentation of the clusters included in DPS and the rationale for inclusion and use.

Cluster/Outcomes	**Rationale and Use**
Change in WEMWBS	Will capture the positive and negative change in carer emotional wellbeing scores from baseline to 6-weeks follow-up. A positive change is suggested by an increase in scores, whereas a negative change is associated with reduced scores.
Change in HADS (depression)	Will capture the change in carer depression scores following 6 weeks of web-based resource use. A positive change in depression is represented by a reduced score. Increased scores suggest an increase in depression.
Change in HADS (anxiety)	Will capture a positive or negative change in anxiety scores. A positive change suggests a reduction in score whereas a raised score suggests increased anxiety.
Change in support for caring (AC_QoL subscale)	Will capture the change in perceived support for carers. A higher score suggests an improvement in perceptions of support.
Change in caring choice (AC_QoL subscale)	Will capture the change in caring choice scores indicating the level of control carers have over their life. Reduced scores suggest a decrease in caring choice.
Change in caring stress (AC_QoL subscale)	Will capture whether there was a negative or positive change in caring stress. A higher score suggests an improvement in caring stress.
Change in money matters (AC_QoL subscale)	Will capture a positive or negative change in money matters following the 6 weeks web-based support use. Increased scores suggest an improvement in money matters.
Change in personal growth (AC_QoL subscale)	Will capture whether there is a positive or negative change in personal growth, highlighting the positive experiences of the caring role. Higher scores suggest carer personal growth.
Change in sense of value (AC_QoL subscale)	Will capture whether there was a change in sense of value. A higher score suggests that carers feel valued and respected, and benefits in the relationship between the carer and care recipient.

Table 4.4 continued:

Change in ability to care (AC_QoL subscale)	Will capture the change in ability to care subscale. This indicates whether carers have report increased ability to care for their relative. Higher scores suggests increased perceived ability to care.
Change in carer satisfaction (AC_QoL subscale)	Will capture whether there is a change in carer satisfaction with their caring role. Improvement in carer satisfaction is suggested by higher scores.
Change in total AC_QoL	Will capture the total change in carer QoL as calculated from the 8 subscales. Increased scores suggest improved carer QoL.

4.3.1 Weekly web-based support use

The first QCA assessed the causal conditions associated with the outcome measures and was outlined in Table 4.4. The causal conditions included in this analysis are summarised in Table 4.5.

Table 4.5. The presentation of causal conditions included in DPS and the rationale for inclusion and use.

Casual conditions	**Rationale and use**
Total weeks of web-based support use	Will capture the total number of weeks support was accessed over the 6-week period.
Total number of times web-based resources were accessed	Will capture the total amount of times resources were accessed over the 6-week period
Total number of web-based resources accessed	Will capture the total number of web-based resources accessed by carers over the 6-week period.
Total amount of time spent on web-based resources	Will capture the total amount of time spent on web-based resources over the 6-week period.

Table 4.6 presents the findings of this analysis and illustrates the prime implicants associated with each cluster. Prime implicants and their connection to the clusters are further explained in this table.

Table 4.6. Presentation of findings from QCA into weekly web-based support use over the 6-week period.

Cluster	**Outcome from Analysis (Prime Implicants)**	**Comment**
Change in WEMWBS (wellbeing)	Prime implicants towards negative or no change in carer wellbeing: 1. Total weeks of web-based support use 2. Total number of times web-based resources were accessed	A higher number of weeks accessing web-based resources and the more these were accessed was related to negative or no change in wellbeing.
Change in HADS (Depression)	There were no prime implicants for a change in depression following web-based support access over the 6-week period. However, there were several tendencies suggesting that fewer weeks accessing web-based support, fewer resources accessed and less time spent on resources was associated with no change or a positive change in depression scores. There were also two tendencies associated with a negative change in depression, specifically less resources accessed and less time spent on these.	
Change in HADS (Anxiety)	Prime implicants relating to a positive change in anxiety: 1. Total weeks of web-based support use 2. Total number of times web-based resources were accessed.	A higher number of weeks accessing web-based support and the more these resources were accessed was related to a positive change in anxiety.
Change in Support for Caring (QoL Subscale)	Prime implicants towards a positive change in support for caring: 1. Total number of web-based resources accessed	Fewer resources accessed and less time spent on these was related to a positive change in support for caring.

Table 4.6 continued:

	2. Total amount of time spent on web-based resources	
Change in Caring Choice (QoL Subscale)	Prime implicants regarding a positive change in caring choice: 1. Total weeks of web-based support use 2. Total number of web-based resources accessed 3. Total number of times web-based resources were accessed 4. Total amount of time spent on web-based resources.	A lower number of weeks accessing online support, fewer amount of resources accessed, fewer times accessed and less time spent on these resources was related to a positive change in caring choice.
Change in Money Matters (QoL Subscale)	Prime implicants relating to negative or no change in money matters: 1. Total number of web-based resources accessed 2. Total amount of time spent on web-based resources	Fewer resources accessed and less time spent on these resources was associated with negative or no change in money matters.

Table 4.6 continued:

Change in Personal Growth (QoL Subscale)	Prime implicants regarding negative or no change in personal growth: 1. Total weeks of web-based support use.	Negative or no change in personal growth scale was associated with a higher number of weeks accessing web-based support
	Prime implicants relating to a positive change in personal growth: 1. Total weeks of web-based support use 2. Total number of web-based resources accessed 3. Total amount of time spent on web-based resources.	A positive change in personal growth was associated with no to little amount of weeks accessing online support, no to little number of online resources and less time spent on these.
Change in Sense of Value (QoL Subscale)	Prime implicants regarding negative or no change in sense of value: 1. Total number of times web-based resources were accessed	Negative or no change in sense of value was associated with more web-based resources accessed over the 6-week period.
Change in Ability to Care (QoL Subscale)	Prime implicants regarding positive change in ability to care: 1. Total number of times web-based resources were accessed	A positive change in ability to care was associated with more times web-based resources were accessed over the 6-week period.
Change in Carer Satisfaction (QoL Subscale)	There were no prime implicants associated with carer satisfaction. Tendencies towards no or a negative change in carer satisfaction were associated with more weeks accessing web-based resources, lower number of resources accessed	

Table 4.6 continued:

	and times these were accessed with time spent on these. Regarding a positive change in carer satisfaction, there were tendencies indicating that no to lower number of resources accessed was linked with time spent on these.	
Change in Total AC_QoL (QoL)	Prime implicants relating to negative or no change in total QoL: 1. Total number of web-based resources accessed 2. Total number of times web-based resources were accessed 3. Total amount of time spent on web-based resources.	Fewer amount of online support accessed, a lower number of times these were accessed and less time spent on these was related to a negative or no change in QoL.

4.3.2 Week of highest access of web-based support

The second QCA considers the influence of demographic factors and the use of web-based support on positive and negative change in carer wellbeing or QoL. This analysis includes week 3 as a factor of web-based support use due to this being the highest access of web-based resources (see Figure 4.1). See Table 4.7 for an overview of the causal conditions included in this analysis.

Table 4.7. The presentation of causal conditions included in DPS and the rationale for inclusion and use.

Casual Conditions	**Rationale and use**
Carer occupation	Will capture carer's employment status, this is separated into employed or unemployed/retired.
Living arrangement	Will capture whether carers live with the care recipient. This also includes whether carers live with other members of the family.
Carer relationship to care recipient	Will capture the relationship between carers and the care recipient, for instance parent and child or spouse.
Hours of care provided per week	Will capture the hours per week spent caring for their relative.
Receipt of support	Will capture whether carers are receiving support at baseline to facilitate them in their role or to promote their health.
Previous use of web-based resources	Will capture whether carers reported previous web-based support use.
Carer recipient health at baseline	Will capture carers' views of the care recipient's health at baseline.
Web-based support use at week three	Will capture carer web-based support use at week three as measured by the weekly diary.

The findings of the second QCA are presented in Table 4.8. Again, this table identifies the prime implicants associated with each cluster whilst also explaining the connection.

Table 4.8. The presentation of QCA of week of highest web-based support access.

Cluster	**Outcome from analysis**	**Comment**
Change in WEMWBS (wellbeing)	Prime implicants indicating no or a negative change in wellbeing: 1. Carer occupation 2. Living arrangement 3. Carer relationship to the care recipient 4. Care recipient health at baseline 5. Hours of care provided per week 6. Web-based support use at week 3	A negative or no change in wellbeing was related to parent carers who were unemployed, did not live with the care recipient, who were unwell, were providing care for under 15 hours, and used the internet for support at week 3.
Change in HADS (depression)	Prime implicants relating to no or negative change in depression: 1. Receipt of support	A negative or no change in depression scores was associated with carers who reported limited support at baseline.
Change in HADS (anxiety)	Prime implicants regarding a positive change in anxiety: 1. Living arrangement 2. Carer relationship to the care recipient 3. Hours of care provided per week 4. Receipt of support 5. Previous use of web-based resources	A positive change in anxiety scores was related to parent carers who lived with the care recipient, were providing care for over 15 hours a week, did not receive support and did not use the internet for support.

Table 4.8 continued:

Change in support for caring (QoL subscale)	Prime implicants associated with a positive change in support for caring: 1. Care recipient health at baseline	A positive change in support for caring was associated with the care recipient being unwell at baseline.
Change in caring choice (QoL subscale)	Prime implicants relating to no or a negative change in caring choice: 1. Carer relationship to the care recipient	Parent carers were linked to no or a negative change in caring choice
	Prime implicants regarding a positive change in caring choice: 1. Carer occupation	A positive change in caring choice was related to employed carers.
Change in money matters (QoL subscale)	Prime implicants indicating no or a negative change in money matters: 1. Receipt of support	Carers reporting no caring support at baseline was related to no or a negative change in money matters scores
Change in personal growth (QoL subscale)	Prime implicants associated with no or a negative change in personal growth: 1. Carer relationship with the care recipient	A negative or no change in personal growth was related to carers who are parent.
	Prime implicants relating to a positive change in personal growth: 1. Carer Occupation	A positive change in personal growth was related to carers who are employed.

Table 4.8 continued:

Change in sense of value (QoL subscale)	Prime implicants regarding no or a negative change in sense of value: 1. Carer relationship to the care recipient 2. Care recipient health at baseline 3. Hours of care provided per week	A negative or no change in sense of value was associated with parent carers who are completing under 15 hours a week caring for someone who was unwell.
Change in ability to care (QoL subscale)	Prime implicants relating to a positive change in ability to care: 1. Carer relationship to the care recipient 2. Care recipient health at baseline 3. Hours of care provided per week	Parent carers who are caring for someone who is unwell for under 15 hours per week were more likely to demonstrate a positive change in ability to care subscale.
Change in carer satisfaction (QoL subscale)	Prime implicants associated with no or a negative change in carer satisfaction: 1. Carer relationship to the care recipient 2. Care recipient health at baseline	No or a negative change in caring satisfaction was related to parent carers who were caring for someone who was unwell
Change in total AC_QoL (QoL)	Prime implicants indicating no or a negative change in total QoL: 1. Care recipient health at baseline	A negative or no change in total QoL was related to the care recipient being unwell at baseline.

4.3.3 Summative discussion

The above section has presented two QCAs identifying prime implicants associated with the impact on carer mental health. Regarding data from the weekly diaries, findings indicated that regular use of web-based resources influenced no change or a decrease in carer mental health. In addition, lower web-based resources accessed and time spent on these was related to an improvement in carer health. The second QCA investigated prime implicants relating to carer demographic factors and web-based support use, using week 3 as the key point of access. There was only one cluster identifying with the use of web-based resources. Carer reduction in wellbeing was associated with web-based support use, carer being a parent, care recipient health, lower hours completing a caring role, unemployment, and living independently from their relative.

Whilst an interpretation of this could suggest that web-based resources do not impact carer health, it is also important to consider alternative explanations. For instance, this could be suggestive of carer supportive needs relating to the caring role. If a carer is distressed, this could result in increased access of web-based resources. Failure to locate useful information or support regarding the situation could contribute to a decrease in emotional wellbeing. An additional explanation is that the QCA suggests the available web-based resources for carers of individuals with schizophrenia and psychosis may not be suitable for carer's needs. Issues regarding available web-based resources, such as lack of quality or unavailability, could have influenced outcomes. This could suggest the need for a specific carer-focussed intervention. Thematic analysis of interviews and qualitative comments from the weekly diaries will provide a detailed perspective regarding web-based resources and the mechanisms regarding their use.

This section will now consider three points of interest from the QCA; improvement in ability to care deriving from the use of web-based resources, influence of carer relationship to the care recipient, and carer employment status in change in emotional health. It is important to note that in the first QCA an improvement in ability to care was associated with increased access of web-based resources. This could suggest the usefulness of web-based resources in completing the caring role and increasing carer confidence in situation management. The following section will highlight the needs-based approach to information seeking and the implications following receipt of information on empowerment and perceptions of control relating to situations encountered in the caring role.

The second QCA identified key factors influencing carer emotional health. For instance, carers being parents was related to reduced caring satisfaction, sense of value, personal growth and reduced wellbeing. Parent carers could be considered to have limited choice in undertaking a caring role. Traditionally, parents expect to provide care for their child until they reach adulthood and independence. The parental caring role in this instance would decrease, however the caring role requires continued care. Alternatively, employment was shown to be associated with increased caring choice and personal growth. One suggestion for this could be employment providing respite away from the caring role and the possibility of a supportive network. Results suggest that context can impact carer health and, by considering this, the likelihood of a positive effect following use of an intervention could be maximised.

The findings of the research informing this thesis will be further discussed and considered in association with the resulting themes from thematic analysis in Chapter six. The following section will present key themes identified from analysis of individual interviews with carers and professionals.

4.4 Thematic analysis of interviews

The following section will detail the findings from the qualitative interviews with carers and professionals. Following the systematic framework proposed by Braun and Clarke (2006) as detailed in Chapter three, a thematic analysis was conducted to identify relevant themes regarding web-based support use and to develop a framework for the construction and evaluation of a web-based intervention. As previously noted, interviews were completed with eight carers of an individual with schizophrenia or psychosis, and with six professionals who regularly work with carers of an individual with an SMI. Table 3.4 provides an overview of participant pseudonyms and demographics.

Participants were invited to review preliminary themes as a member-checking process. Member checking can involve participants reviewing written transcripts or a summary of themes to ensure accuracy and consistency with views (Birt et al., 2016; Thomas, 2017). Similar to triangulation, member checking is considered a method of ensuring quality in qualitative research (Creswell and Miller, 2000). Twelve participants consented to the member-checking process; one professional was lost to follow-up and two carers declined. Three participants agreed that the provisional themes reflected their views. The

remaining participants reported that findings included unfamiliar experiences, however acknowledged that their views had also been incorporated and deemed this acceptable.

On the basis of the analysis process set out in Chapter three, five themes were identified;

1. Expertise via experience: considers the role of web-based resources on empowering carers and the relationship between carer and care recipient health.
2. Empowerment through knowledge: focuses on information seeking and its relationship with carer empowerment.
3. Connection, understanding and advice online: focuses on the communication aspects of web-based support.
4. Personal preference - considering the accessibility of the internet: focuses on the accessibility of the internet and the possibility for a person-centred approach to support seeking.
5. The landscape of carer support: focuses on available web-based support for carers and the role of appraisal and financial barriers.

These themes will be defined and presented below with example quotes from individual interviews. Themes are of equal importance and not presented in a particular order.

4.4.1 Theme 1: Expertise via experience

The first theme is expertise via experience and is defined as the recognition of carer idiosyncratic knowledge acquired through undertaking the caring role and the transition of equal power distribution in the healthcare setting. In doing so, this considers the reflection to the beginning of the caring role and the use of web-based information to manage situations encountered throughout the caring role.

This theme included four subthemes;

- Reassessing the balance of power.
- Focusing on the beginning.
- Dealing with situations.
- The relationship between carer and care recipient health.

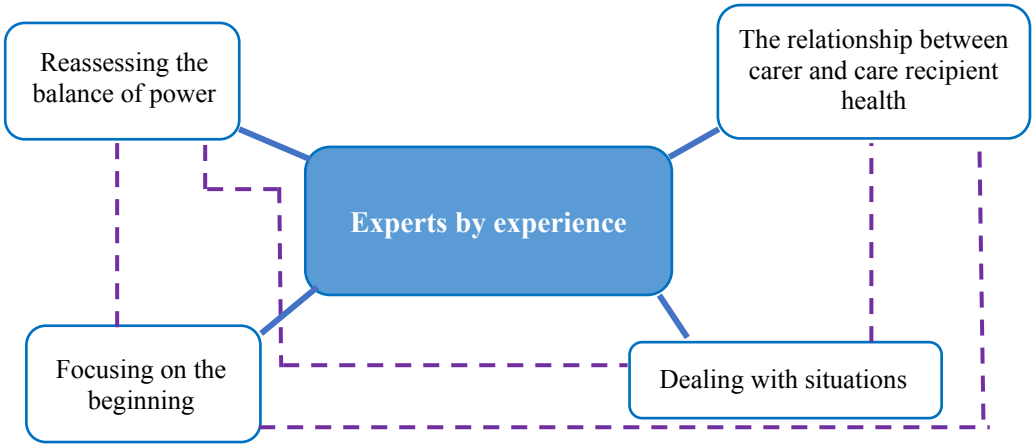

Figure 4.2. A visual depiction of interplay between subthemes in the theme experts by experience.

The above figure presents four subthemes and relationships between these. The four subthemes are defined and illustrated below with relevant quotes from individual interviews.

Focusing on the beginning

Carers often referred to the beginning of the caring role when their relatives were initially diagnosed with an SMI, often describing this as a distressing experience:

> *'…it was fairly horrifying to find out that he had… an incurable, chronic condition, that was going to get little better, that might not get any better, that, that he might be hospitalised for the rest of his life…' (Eddie, carer interview)*

> *'… my husband had really quite severe psychotic depression and I knew nothing about this… I knew a little bit about depression, I didn't know anything about psychotic depression and it's frightening… it's really scary, and when people are discharged from hospital, they're discharged when they're still not well… and the mental health team took a while to pick him up, and in that time, you're on your own. Erm you just think, well what do I do?' (Maria, carer interview)*

However distress was not solely related to diagnosis:

> *'I mean my son had been diagnosed, almost 10 years by then and I had been struggling along, didn't have a clue really what I was doing, or how to help him, or what to do, I was just scared all the time' (Rosa, carer interview)*

> *'I think there is a need for online support throughout the caring role because, I mean, we're now 21 years down the road… and I still feel stressed at times, I still don't know what to do and you still feel isolated at times…' (Maria, carer interview)*

This carer described the importance of acceptance of the care recipient's illness before seeking support:

> *'...you don't want to accept in the first instance that this is what's happening... you've got to come to terms with it before you can start doing a lot of research on it.' (Lynn, carer interview)*

Family members also needed to accept their new role as a carer:

> *'...if people have been in the role and actually identify themselves as being a carer because that's another issue that ... we come across a lot ... often people say "Well I'm the wife, I'm the husband, I'm the daughter, the son, you know, I'm not a carer", so it's hard for people to identify themselves in that role in the first place (Ella, carer interview)*

Carers reported a need for knowledge to assist them in undertaking a caring role, however they also noted limited support from healthcare professionals. This resulted in carers learning through experience:

> *'... actually ours has been 17 years of learning so everything that I've talked about here, we've picked up ourselves as we've gone along... I don't think the people who are new to this, that is still very available...' (Heather, carer interview)*

Whilst noting that some web-based information was useful, carers reported that some would have been more useful when initially beginning a caring role:

> *'Lots of general information which I could have used when I started caring.' (Eddie, carer diary, week 4)*

Carers identified the importance of self-care and information-seeking over the course of the caring role. However, they also continued to suggest that ongoing support and intervention would be valuable.

Reassessing the balance of power

Despite the transition into collaborative-based healthcare, some carers reported reliance on healthcare professionals to provide information and support:

> *'...people will often say to me "Where do you recommend? Where do I look?' (Lee, professional interview)*

This was especially prevalent at the beginning of a caring role. Failure to provide this information could negatively impact the carer-professional relationship. However, this could indicate the traditional balance of power in the healthcare setting, where professionals were placed in a more powerful position due to their knowledge and skillset.

As a result, patients and family members were placed in a less powerful position. This professional went onto to highlight the continued power imbalance in healthcare:

> *'I feel like, erm there's a power gradient, you know, like there's these professionals… who do know loads about psychosis and then there's patients and carers who are in a less powerful position because they don't have the information and that's crazy, it shouldn't be that way in 2017…' (Lee, professional interview)*

This professional argued for complete disclosure of information and the subsequent removal of the balance of power. Access to web-based information could increase carer perceptions of control in managing the caring role. When reflecting on this point during the member-checking process, this professional illustrated the difficulty of information disclosure in relation to treatment and concomitant side effects. This indicates the importance of transparency to facilitate choice while concomitantly minimising distress.

Healthcare professionals encouraged a self-directed approach to seeking web-based information, seeing this as facilitating discussions and promoting a collaborative approach and carer empowerment. Carers were reported to have accessed information prior to their relative's initial assessment:

> *'I'd say 9 out of 10 people, yeah 90% of our service users have googled psychosis before they even meet us and we meet people really quickly, like we generally see people within a week of referral…' (Lee, professional interview)*

The availability of web-based information could indicate a change in the traditional balance of power, with professionals no longer being the sole provider of support. Healthcare professionals appeared to promote this empowerment by encouraging carers to complete a self-directed search for web-based information:

> *'I think it's a rule of doctors who see patients to tell carers about the relevant websites and… to encourage them to… even use google and er Chrome… and stuff like that just to search…' (Robert, professional interview)*

However carers viewed a self-directed search for information negatively:

> *'I've got to say though there was nobody in our local help had a clue what I was doing, nobody directed me to any, any of these sites or made any attempt to educate us at all, I had to do it myself.' (Eddie, carer interview)*

Despite this, technological advancements, such as podcasts or web-based seminars, were seen as possibly promoting collaboration:

> *'… I like the idea of a professional having a discussion with the carer… someone's who's got very experienced… have an interview if you like,*

between a professional and a carer… and with a chatroom discussion afterwards…' (Robert, professional interview)

'I think sometimes things like podcasts and things like that are… a good erm way of sharing things, they can be really personal, you know it's quite intimate, someone talking in your head... about stuff, having a conversation…' (Lee, professional interview)

The ability to post or view questions could be vital to carers who would otherwise be unable to access this information. Additionally, as illustrated in the above quote, the internet could allow the ability to connect directly with professionals to discuss concerns.

However, carers reported not being involved in discussions regarding their relative's care. Relating to their support needs, carers acknowledged that professionals have limited time to provide information. This could suggest that professionals place a priority on the care recipient, as opposed to addressing carer needs.

This professional described differences between carers' and professionals' perspectives:

'…one of the issues with families is that they feel responsible… there's this kind of emotional extra layer that means that perhaps they're not able to detach from the situation and look at it in the same way a professional would… and also the professional would, have got a team to go back to and somebody to talk to, they don't take personal responsibility for what's going on like the family do…' (Linda, professional interview)

This could indicate that professionals may struggle to understand carers' situations, which could increase conflict. The professional highlighted the usefulness of supervision and carer lack of support network, suggesting that this difference could impact adherence:

'Researcher:… so you think the divide between carers and professionals could potentially be an issue when making an online intervention?

Linda: I think that if your online intervention is written by professionals then yes it could…'

The above quote suggests the importance of collaboration and including content and personal perspectives from carers of individuals with schizophrenia or psychosis within the web-based resource. Inclusion of carer-specific content could demonstrate an understanding of the carer's situation and associated distress. The construction of a web-based resource that only includes content provided by professionals could deter carer usage. One carer also highlighted the importance of carer engagement and feedback in service provision and training to improve professional understanding:

'Because I know some carers are very interested in getting involved in sort of developing new strategies or telling their stories, for example in training of

> *erm new staff, erm I think that can be useful on two fronts. It can be useful for the carers themselves to actually tell their stories and also for new staff to be erm aware of what it's like being a carer… [referring to construction of a web-based intervention] it definitely would be useful to keep carers of… at different stages and levels involved throughout the process…' (Heather, carer interview)*

However, one carer noted the importance of professional involvement when seeking support:

> *'…I suppose I knew there was a carer's group but I didn't really consider it until the care coordinator said "Now, what are you doing to get some support for yourself?... Here's the number of the local carers group." I could have easily looked it up myself but it was getting a prod into someone saying "This will help you"…' (Lynn, carer interview)*

This carer appeared to have a positive relationship with a healthcare professional, describing information exchange about the care recipient's health occurring via email. As demonstrated in the above quote, this was also beneficial in encouraging the carer to attend support to improve their own health. This could indicate the influence of human involvement in support seeking; which could be difficult to implement in a web-based intervention.

One carer designated a preference for the traditional balance of power:

> *'…I'm waiting for people to tell me… I think it's got to come from professionals… and there are people doing… some work on this… I think they're the people you ought to go to…' (Eddie, carer interview)*

The above quote suggests that this carer continued to view professionals as information providers due to prior training and expertise. This further suggests that carers do not view themselves as experts by experience, despite holding a caring role over a period of years. For instance, the above carer was an active user of web-based resources and reported searching for information about schizophrenia. Professionals from charitable organisations also raised this as a barrier, highlighting the difficulty in sharing information about carer support networks. The view of professionals as experts could be indicative of professional qualifications, and carer concerns about acting incorrectly. However, an overall failure to provide information could negatively impact the carer-professional relationship.

Dealing with situations

Participants reported the importance of including information relating to symptoms, diagnosis and treatment. However, one carer reported failure to access this:

> *'... I think in terms of information about the illness, erm and how to respond to it is quite useful online which I don't think I've bothered to read, even after all of these years, I never really looked before because dealing with the day-to-day situation…' (Lynn, carer interview)*

This carer suggested implementing a firefighting approach to the caring role; particularly via individual searches regarding current need as opposed to preparation. These participants discussed the need for information regarding managing situations:

> *'…you don't know how to respond when, when somebody tells you that they're solid, and you're thinking, "Well hang on, how do I respond to that?" You know and I was always worried about doing more harm… do I challenge it? Or do I just go "yeah, yeah you are" or what?" (Maria, carer interview)*

> *'Used it to try and find out how to respond to delusional fantasies' (Lynn, carer diary, week 6)*

> *'I still cannot find any advice on what to do about my sons residual symptoms which are persistent and distracting for him.' (Eddie, carer diary, week 5)*

> *'... And nobody says anything, around here anyway, to families about how they handle particular situations, I mean if somebody repeatedly says "I'm going to kill myself" what do you say back? How do you handle that? What, what are your choices, what opinions have you got to approaching it?' (Linda, professional interview)*

Participants requested information on responding to self-harm and communication difficulties. The above quotes imply that there was a correct way of responding to the situation, with carers reporting concern that acting incorrectly could negatively impact their relative's health. One participant reported the difficulty providing information relating to mental health during the member-checking process. Noting the contrast to physical health, this participant highlighted the limited availability of mental health information and the difficulty ascertaining any immediate positive outcomes. Lack of knowledge regarding these situations could increase feelings of powerlessness and affect carer emotional health. One professional suggested the importance of providing this information on user adherence to a web-based intervention:

> *'…if you had a section on my daughter won't come out of her room, she's not had a bath for 6 weeks and, erm, the sheets haven't been changed and she won't eat anything but cold pizza, then you would have thousands of hits…' (Linda, professional interview)*

Professionals reported that there were web-based factsheets concerning this issue available, however it was unclear whether the carers in this sample had accessed these. One participant suggested there should be guidance in implementing web-based information in real-life situations as this may not be clear.

This professional argued that carers should be trained to respond to situations:

> *'... some sort of training, I think if the carers in the community... pick up this burden left over from cutting services, then train them in the same way we would train mental health professionals... having a good programme for training of carers in our community where they can access university courses as well would be great, because they are basically doing the job of mental health professionals, a lot of them.' (Chloe, professional interview)*

There could be a debate regarding the appropriateness of training carers in skills similar to those of mental health professionals. Presently, carers support their relative outside of professional contact, and often with no prior healthcare training. By providing training to carers, this could promote knowledge and empowerment, which could also impact on carer mental health. However, this would make the following assumptions. First, that carers are willing to undertake a caring role and that their relative accepts their assistance. Second, that carers are able and have the capability to complete training, and that funding is available. A third and final consideration is that carers are able to objectively treat their relative with minimal impact on their own health.

The relationship between carer and care recipient health

These carers described the relationship between their own and the care recipient health:

> *'... he becomes stressed about the impact of his health on mine... it's really difficult because you don't want him to become stressed about you... but it's kind of like how the hell do you, how do you stop them?... in turn that will make them feel more unwell, so you've got this beautiful vicious circle going round and you cannot kind of get out of it...' (Maria, carer interview)*

> *'I suppose you kind of relate back to, you always link back to the person you care for and you're always thinking of improving their quality of life, which then has a knock on effect to improve your quality of life...' (Heather, carer interview)*

Although one carer reported that their relative was not concerned about their health, others acknowledged that their health was affected by situations encountered in the caring role. Carers reported distress, particularly during initial diagnosis. This could indicate that a joint intervention developed for carers and individuals with schizophrenia could be beneficial for carer and care recipient health. The above quote could further suggest that by increasing carer health, this could improve the health of the care recipient.

However, carers questioned whether their wellbeing or QoL could be improved whilst undertaking a caring role:

'...a cure would improve my quality of life a great deal… knowing my only son… his life is completely wrecked, he has no relationships, er no job, no money, er he spends all the time completely on his own… if we didn't see him for 3 days, he'd go for 3 days without speaking to anybody… what would improve my quality of life is a cure…' (Eddie, carer interview)

'...in terms of wellbeing… I suppose the only thing that is going to make me feel incredibly well would be either my son totally recovers… or somebody else takes over the (laughs)… day… to day kind of dealings…' (Lynn, carer interview)

Participants suggested that a web-based resource should include advice and information regarding carer self-care or how to implement therapeutic approaches, such as CBT, to influence behaviour change. Professionals reported available web-based resources that aimed to improve carer health. However, it could be difficult to encourage adherence:

'...I suppose information about your own… wellbeing and how to… look after your own wellbeing, which I know people do give you a lot of information about, but it takes, it takes quite a lot of getting through… to people because having spoken to a lot of carers, carers do put themselves last because… they're always thinking about what they've got to do to keep everything on the level for the person who they're caring for… and erm, the carer's emotional wellbeing comes well down the list…' (Heather, carer interview)

The above quote suggests that carers prioritise their relative's care over their own emotional needs. These professionals further described barriers to encouraging carers to focus on self-care:

'...it's about recognising that, you know, that they've got their own life as well, and encouraging them that it's not selfish and they don't need to feel guilty if they want to go to the cinema… a lot of people again might cancel holidays because of an inpatient admission… and it's like actually if they're an inpatient then that's the time to go, like they're safe, they're being looked after, you don't have to then sit there worrying about them for 2 weeks but obviously they're going to but people feel guilty for having a life for themselves…' (Chloe, professional interview)

'...so it's about stepping back and saying maybe this isn't going to change for a while… you can do a few things to encourage someone but you can't make them do it, so in the meantime, it's OK if you have a social life or you know have a proper diet… that isn't selfish, that's self-preservation and if you want to be there to look after her in a years time, it's better if you stay in good nick…' (Linda, professional interview)

These quotes illustrate that carers may require permission and encouragement to focus on their emotional needs. This could further indicate that carers may display over-responsibility for their relative, deriving from guilt or familial duty. Consequently, there was a focus on improving their relative's health, in some cases seeking a cure for schizophrenia, as opposed to considering their own supportive needs.

Summary

Figure 4.2 presented interlinks between subthemes. Professionals appeared to promote a self-directed search for information at initial diagnosis and situations regarding the caring role, however carers reported limited support to facilitate this. As a result, this could negatively impact relationships with professionals, leading to one participant to emphasise the importance of carer input to promote adherence. Carers highlighted the development of expertise via experience over the course of the caring role. The development of this expertise with the promotion of a self-directed search for information could increase carer empowerment and promote collaboration between carers and professionals. One professional further argued for carers to receive training similar to that of healthcare professionals to further assist in the management of the caring role.

There was a connection between dealing with situations and the relationship between carer and care recipient health. Carers reported that situations encountered throughout the caring role impacted on their health. Situations included initial diagnosis or were related to their relative's health, for instance symptoms such as hallucinations. There appeared to be an assumption that acquiring knowledge could increase carer control, which could impact on their health.

4.4.2 Theme 2: Empowerment through knowledge

Empowerment through knowledge is defined as the search for information that, if received, is perceived as increasing knowledge for managing the caring role, and therefore increasing carer empowerment. This theme also considered the value of high-quality web-based information and the impact of the receipt of this information on the carer and care recipient.

There were four subthemes within this theme;

- Crash course in psychiatry: Needs-based approach to seeking information.
- "Reading horror stories": Considering the quality of web-based information.
- Topics for inclusion.
- "The world opened up": The value of knowledge.

The relationship between these subthemes is demonstrated in Figure 4.3.

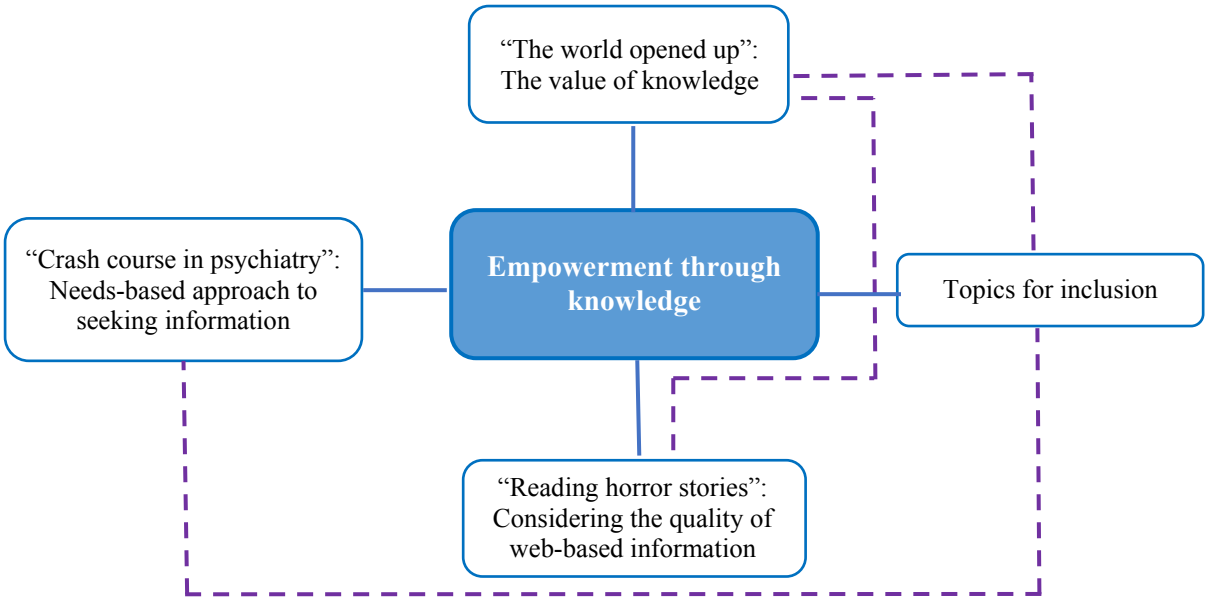

Figure 4.3. A visual depiction of the interplay between subthemes within the theme empowerment through knowledge.

"Crash course in psychiatry": Need-based approach to seeking information

Carers reported a needs-based, or problem-solving, approach to searching for web-based information. For example, a carer encounters a new situation such as initial diagnosis of a mental illness or their relative experiencing hallucinations. This situation could result in a negative response, for instance stress or fear, especially if the carer had limited knowledge prior to this occurring. By searching for web-based information, carers appeared to be implementing a problem-solving approach. Acquiring information was perceived as helping overcome the stressful situation. This carer described information seeking following initial diagnosis:

> *'OK, well the first thing I did when my son was diagnosed is to go online and found out as much as I could about it, there is quite a bit… so I found out quite a lot about schizophrenia, all the sets of symptoms and the… side effects of all the drugs and everything, especially clozapine because that's what my son eventually end, ended up on… we did look at areas such as different services advice, finances, the law, stuff like that…my wife and I took a crash course in a very, very narrow area of psychiatry…' (Eddie, carer interview)*

Searching for information continued throughout the caring role:

> *'Over the years I have I have used the internet to research schizophrenia, its symptoms, prognosis, medications etc.' (Eddie, carer diary, week 2)*

The above quote highlights the available web-based information regarding schizophrenia. Whilst this refers to written information, content was also available through videos and personal blogs which could increase understanding. Example topics included symptoms of schizophrenia, medication, carer support and stigma. Whilst the above quote related to beginning a caring role, a problem-solving approach to information seeking could occur in response to situations throughout the caring role:

> *'...I've accessed information, erm, because my son was due a review for PIP... I accessed quite a lot of information online about that... from different sites... to see what kind of questions were asked... to see what to expect...' (Stella, carer interview)*

A needs-based approach could also include searching for understanding from others with similar experiences:

> *'...one of the things that always emerges quite quickly is that sense of being completely on their own with this, often for 20 years, 30 years erm and having had very little support either from the rest of the family or neighbours who have not been close enough to really understand what's been going on, so they kind of backed off or taken a very judgemental role...' (Linda, professional interview)*

The above quote emphasises the importance of support groups for carers of an individual with schizophrenia or psychosis. Although this quote focuses on non-web-based support groups, this could indicate the need to identify a technological alternative that could increase the ability to communicate. This could be particularly valuable for carers unable to travel due to work commitments or the inability to leave the care recipient.

One carer noted that needs changed depending on the situation and the care recipient's health:

> *'...a lot of people's conditions fluctuate so that the carer may come to an intervention at a stage where things are going OK but then they might hit a bad point...things aren't always a steady line of progress it's ups and downs...' (Stella, carer interview)*

> *'...I think your needs change because you become... more attune to the person, you kind of get used to that role... but there's other difficulties come, erm for example, what would be my rights, you know, with regards to employment?... And I have absolutely no idea and I have no idea where I would find out... so if my husband became unwell again you know, what do I do? Do I ask for carer's leave?' (Maria, carer interview)*

Therefore, it could be inferred that supportive needs may vary. This could indicate a need for different forms and intensity of support depending on the situation. Thus, this further indicates the difficulty assessing the impact of a web-based intervention via an RCT that

typically advocates a minimum amount of access over a long period. Whilst useful during a difficult period, carers may be less likely to access support if a need was not identified.

Carers noted several barriers to seeking web-based support, such as lack of time. However, one carer stressed the importance on a needs-based approach regarding overcoming barriers:

> *'But if I had the need, I would do it, I would find the time… it would be need-led… if there was a change or if there erm was a situation where I thought "well actually I could do with having some information here before I go out… and look for things as well", then I would find the time to use it and that's why I think it would be really useful to have it there… available but I just haven't had that need in the last 6 weeks to make the time…' (Heather, carer interview)*

Whilst the above quote suggests that the identification of a need could overcome some barriers, the below example indicates that the emotional response to the caring role could prevent usage:

> *'…other barriers might be just that they're so overwhelmed with the caring situation that they're, they haven't time or motivation to get on a computer…' (Stella, carer interview)*

Although this barrier could occur in non-web-based support, the autonomy of the internet and lack of an external influencer (such as a healthcare professional) could affect adherence.

To complete a needs-based approach, participants highlighted the ability to find web-based information through search engines:

> *'…there's a really high likelihood that people are typing erm symptoms into Google if they are experiencing them or carers as well you know, if, if your son or daughter says "mam, I'm hearing voices", erm I'd be very surprised if people didn't type that into Google, erm and so, that's what people have reported to us as well you know like, they'll type in 'voice hearing' or they'll type in er paranoia', 'anxiety', 'depression' and amongst a range of you know, amongst a range, a range of conditions, erm psychosis will be in there…' (Lee, professional interview)*

> *'…when somebody's erm maybe first new to the role or their loved ones either been detained in hospital or had their first, sort of, onset of being ill, people might not know Rethink or Mind, you know, but they might google…"I'm a mother and my daughter has depression, what do I do?" or something, you know…' (Ella, professional interview)*

Searching for web-based information could increase carer empowerment and control over a new unfamiliar situation, potentially leading to service referrals:

'...it gave me a sense of empowerment because ...you actually feel you're getting somewhere that you've got some information or you've got some, erm, knowledge that you didn't have before... and you know what the next step is, so it can make you feel like you've got a little bit of control over things... you're finding information for yourself and that you're not dependent on other people or you're not quite as lost as you were. (Stella, carer interview)

However, carers may not recognise the use of search engines as a form of web-based support:

'Researcher: ...so is there any particular reason why you didn't look at online support before?

Lynn: Erm ... I suppose I might have Googled things but... I wasn't aware of the websites that existed...'

The above quote indicates that web-based support is viewed as a specific resource as opposed to general information searching. This could further signify the prevalence of search engines in everyday life.

However, carers and professionals reported missing information using a self-directed approach:

'...I always googled schizophrenia, and I was looking for sites on schizophrenia, it's only recently I've been looking for sites on carers... it didn't occur to me, that er you know, they would be separate...' (Eddie, carer interview

'...often people will come to us er actively aware of things like psychosis and schizophrenia but the thing which is lacking... they'll know the symptoms and the diagnosis but they won't know the treatment options, erm or they won't know many of the treatment options...' (Lee, professional interview)

These quotes indicate that carers focus on topics relating to schizophrenia, illustrating an attempt to gain control by understanding the illness and how to effectively respond to situations. Information about available treatments could be perceived as being within the professional's remit due to training and experience, and therefore could refer back to the balance of power. However, the missing of key information could have resulted in this carer missing valuable support.

Another carer outlined the perceptions of usefulness in adherence to a web-based resource:

'...I looked on but didn't discover anything of use... to be fair I didn't try it so it might have... been useful...' (Rosa, carer interview)

This quote could suggest that if a resource is not perceived as initially useful, it would be discarded. This may indicate gaps in knowledge and limited access to information that could be useful for their caring role or in a crisis.

Topics for inclusion

Professionals noted that although information regarding schizophrenia or psychosis was available, they still viewed it as an important compontent in web-based interventions;

> *'... a little bit of education, information, erm, some facts as well, like fact sheets or… information available, what to do, erm how to look out, you know signs of symptoms and, or relapse…' (Ella, professional interview)*

Suggested topics included possible causes, treatment options, success rates, expected NHS involvement, statistics, prognosis, identification of symptoms, and definition of key terms. Another professional emphasised the importance of developing carer understanding of the care recipient experience:

> *'…I'd like case studies and like real-life experiences… patient's perspectives on it, erm like one of the most common things people talk about is erm "I don't know what they're thinking" like a carer would say "I don't know what my son or daughter is thinking, like they're really quiet, they won't tell us what's going on inside their head and I don't understand it, I don't know what to say to them..."…' (Lee, professional interview)*

For the carer, this could influence the appraisal of schizophrenia, potentially reducing fear and increasing knowledge. As a result, this could impact carer wellbeing and QoL.

Other participants suggested the need for practical information:

> *'...they need information about the role of carer and the work, what their rights are, carers assessment, you know the employment law, benefits… the information about benefits and assessments are all out there and very well documented I think… they've all got pages and pages on that and it's fairly accessible…' (Linda, professional interview)*

> *'...I think it also has to have a practical component… if you get practical information and, you know, information about benefits and housing, things like that really practical stuff, that in turn will help to reduce the stress levels… you know where you're going and you know what to ask for… that does make a big difference…' (Maria, carer interview)*

Whilst this information was also reported to be available via the internet, there could be difficulties locating this due to the lack of a centralised resource:

'I suppose the easier you make it for someone to access something… with a kind of central access point, the easier it is for anybody even someone who's computer literate I suppose, rather than having to search different things each time differently…' (Lynn, carer interview)

'I haven't needed to access online support that much, I guess, once or twice a week erm and I haven't really been able to spend that long on it, but if that information wasn't on millions of websites but all on one place then that would have been a real help…' (Maria, carer interview)

Professionals also suggested support to assist carers in attending appointments and to encourage them to seek support regarding their health needs. Carers requested advice about the caring role to improve carer and care recipient health. This could indicate that although information was beneficial for understanding, there remained a need for a problem-solving approach. Examples for achieving this could be directing carers to services for assistance or promoting self-directed changes that carers could implement. These self-directed changes appeared to relate to the carer's own situation, however there was a debate about whether this could be achieved via a web-based format.

One carer suggested the need to provide information about carer entitlements and resources to contact for further information:

'…some apps with some practical information, you know, these are the people that can help you, there is a… carer's hotline at any time… Well no one told me that you're entitled to carers allowance… and nobody tells you how to claim it, nobody… tells you about you're entitled to a carer's assessment… by the person who's working… working with you, erm nobody tells you where to get some respite from… if there's some availability to, to carer support workers, erm and I know they exist but I've never been offered one…' (Maria, carer interview)

Carers also noted the importance of providing information concerning professional roles:

'…who you could expect to come across, I mean things as simple as what different roles people might play… we were thrown in completely at the deep end and we had no idea who anybody was or what anybody did… they were saying you know "I'm the, uh, clinical psychologist"… I didn't know what a clinical psychologist was, but what was their role?' (Heather, carer interview)

'…if you find yourself in a position for caring, is who should you be in touch with? And who do you have a right to be in touch with?... And at what point should you be included in any discussions? Now that happens automatically when someone is erm in hospital … but once someone is outside of a hospital, who do you have a right to talk to? Who should you be communicating with? Is it the consultant who's in charge of the group? Is it the care co-ordinator? Is it a district nurse?…who is it that you should be talking to regularly, who should be supporting you as well, or your, your relative or friend? (Lynn, carer interview)

There was an assumption that provision of this information could provide realistic expectations regarding professional capabilities and responsibilities. This understanding could reduce relationship strain and promote a collaborative approach between carer and professionals.

Several carers suggested providing information regarding expectations:

> *'...to tell people what they're going to feel because nobody tells you and nobody tells you what to do, and OK, you know, they can't tell you what to do but they could give you some ideas on what not to be frightened of…' (Maria, carer interview)*

> *'...what you can expect as a carer, sort of how much involvement you can expect ... and actually what the barriers are…' (Heather, carer interview)*

This could be about present and future situations, and the emotional response to these. However, participants advocated the importance of providing hope:

> *'...I think that very often that it's really important that there's some kind of messages of hope… I think that very often that is something that is really difficult to get that but that is so important for families and carers… and I don't know how that can be put onto an online support website, whether that is messages of hope from other people's stories or messages of hope that things can improve but quite often that is one of the main questions that carers come with…' (Heather, carer interview)*

> *'...if you can engender hope in somebody by any means, I think that's better, it's a really powerful and positive thing arguably more powerful than any medication. I meet so many carers who are hopeless… and that is communicated to the patient… if you find a way of, you know, helping somebody understand in a really accessible and thorough way what psychosis is, that this is you know, erm really common, it's totally recoverable, you're able to recover from it… that improves the patient's life, you change that carer's life…' (Lee, professional interview)*

> *'... carer story kind of website resource would be really useful… Give people hope, erm I think it would make people feel like less afraid, because a lot of people are quite, yeah it can be a very lonely place especially if someone's in their first inpatient admission or something… there are carer stories but they're very generic, I think mental illness is very different to other… there's a lot of misunderstanding out there generally so having online stories I think or any published material so people realise they're not the only one and try and encourage, encourage people to talk about it…' (Chloe, professional interview)*

Although participants highlighted the importance of providing hope, they stated that this should be realistic. Participants also suggested that web-based information from others could demonstrate progress and increase knowledge, but noted that this could be difficult to find. There was concern that only providing professional viewpoints could alienate

carers, and therefore professionals suggested the importance of providing carer stories. Lee stressed the importance of quality, balanced and rich information on hope promotion.

This professional stated the importance of a strength-based approach:

> *'…there needs to be something in there about building upon the strengths people have, you know carer show tremendous resilience, they've got a wealth of erm problem solving techniques which they kind of develop themselves so it's a kind of allowing them to, to build on… those strengths.' (Jim, professional interview)*

This could encourage carers to recognise and build upon their skills in managing the caring role. The promotion of carer skills could increase confidence in their caring ability and influence interactions with the care recipient, therefore influencing carer and care recipient wellbeing. Another professional stressed the importance of providing carer feedback:

> *'… so for carers to get positive feedback about how well they're doing and what they're coping with, is really very very rare…' (Linda, professional interview)*

Carers raised the importance of providing questions:

> *'You set out on this journey and you don't know who you should be asking questions of and you don't actually know what questions you need to ask, until you're thrown into a situation and it's very often a long time before you can actually get to speak to somebody to ask the questions…' (Heather, carer interview)*

As can be seen from the above quote, web-based resources could provide the opportunity to ask questions that may not be available within non-web-based support. For example, this could be the inclusion of a question and answer section. The availability of this section could then facilitate carer preparation, increasing their ability to perform and control caring situations.

"Reading horror stories": Considering the quality of web-based information

There was more focus placed on the quality of web-based information by professionals compared to carers. Despite this, carers acknowledged the varying quality of web-based resources. One carer defined what they perceived to be a reliable resource:

> *'A [reliable] source that has been recommended by the mental health authorities, psychologists and mental health specialists… They are the right*

people. They have all the experiences and knowledge.' (Brian, carer interview)

This quote appears to refer to the traditional balance of power in a healthcare setting that places professionals in a more powerful position due to knowledge and skills. One professional suggested that the perception of this relationship could influence the use of web-based information:

'…sometimes carers feel… they are kind of erm, you know not doing the right thing by er checking up on what the doctors are saying by looking at the internet but really it should be quite the opposite… kind of the old fashioned kind of cultural assumption that the er what the doctor says goes… with any other service trade, you know, you would be expected to look around and check… there's this kind of power imbalance or information imbalance and having access to internet should sort that out really.' (Robert, professional interview)

Despite this, the carer sample appeared to be confident in determining the quality of web-based resources with participants, referencing peer review and the need for evidence. However, participants acknowledged that this might not be the case with other carers. One suggestion of which could be their limited experience in the identification and judgement of quality web-based resources. Professionals raised concerns regarding carers' abilities to find quality information:

'…sometimes it's difficult I think for people to find the right information and also there's a lot of rubbish online also, well erm and people can get themselves into some, some states reading horror stories and things like that but then again that's responsible use of the internet, isn't it? And understanding about good sources and not so good sources…' (Chloe, professional interview)

'…that there's like a poverty of information out there, there's not reliable NHS kind of erm authored information out there, there's lots of third party stuff and it's of questionable like veracity and quality and stuff so erm having something that was from a reliable, a reputable source and was pretty, er, you know far reaching in terms of what it's talking about…' (Lee, professional interview)

Professionals reported that web-based information, such as newspaper articles, could spread bias or fear:

'…Carers going to search for it, they'll just Google erm, symptoms or signs of psychosis…but things that can go to the, kind of top of the Google search can be opinion pieces, do you know, like a newspaper article maybe or erm a forum post that's been viewed loads and loads of times…distressing instances, someone being unwell when they stabbed somebody… so these types of search results will filter to the top and you can imagine as a carer… that's going to really affect the way you interact with your caring role…' (Lee, professional interview)

There was concern regarding the impact of negative information and misconceptions of psychosis on carer health, and the subsequent impact on care recipient's health. This could result in delays seeking or the rejection of recommended treatment due to negative content available online. Therefore, one professional emphasised the importance of providing good-quality information to carers, observing that this could promote hope and carer health which, again, could affect the care recipient's health.

However, this professional suggested that this concern was not necessary:

> *'...people are generally sensible and will check and countercheck validity of information… certainly with mental health conditions… on the whole the information provided is reasonably valid and you don't get kind of crazy opinion being preferred in my experience… So even if you go on a Google search, you know, you can't go too wrong… you're not going to get seriously misled…' (Robert, professional interview)*

One interpretation of quality assessment and information seeking could suggest that carers undertake a similar role to a researcher. Carers reported actively searching for information regarding the caring role, illness and support available. Information seeking appears to be supported by healthcare professionals, however there remained concerns regarding quality assessment or understanding of web-based information. These skills are common as a researcher, however there is an assumption that carers would be able to determine quality when this may not be the case. This is not to suggest that web-based information should not be accessible to the public, but the ability to understand and critique resources should be encouraged and shared.

Professionals praised reliable web-based resources such as charity organisation websites. One professional noted that organisations were attempting to engage the public. This could be perceived as an attempt to remove the ivory tower and facilitate knowledge exchange, addressing the power imbalance between the public and professionals:

> *'...Cochrane is very keen for the general public to access their, their reports…so I mean, you get kind of 50 top of the range kind of evidence base available for ordinary people…' (Robert, professional interview)*

However, carers reported encountering bias through web-based resources:

> *'…what does happen is… some company will, will send out a press release on the particular medication… that they er produce and it's all wonderful… if you've got any sense you'd ignore all that… and wait until everything's properly peer reviewed and properly tested, so it's easy to be led astray...' (Eddie, carer interview)*

As can be perceived from the above quote, this carer appeared to be frustrated by perceived incorrect, negative or biased information they encountered online, which could influence appraisal and adherence to support. This could be through pharmaceutical or university web-based resources. It is important to note that perception of incorrect information could relate to one carer's theory regarding the cause of schizophrenia:

> *'One chappie was totally convinced that schizophrenia was caused by trauma … right, environmental factors, and he looked at a lot of cases and he found in every case that something had happened, you know, that his parents had got divorced or his dog had been run over or something and according to him, this is what had caused the schizophrenia… total nonsense of course, er easily disproved er and there were still a few people er giving an older view…' (Eddie, carer interview)*

The above quote suggests that carers searching for web-based information may be subject to a confirmatory bias; i.e. searching for information to support an initial viewpoint. By not considering environmental factors towards the development of schizophrenia, this could indicate the popularity of a medicalised perspective of mental illness or that the carer was unaware of the relevance of this towards the care recipient. Alternatively, this could also indicate an attempt to mitigate carer guilt towards the development of schizophrenia, for instance following a divorce in childhood.

In relation to intervention construction, participants suggested that content should be based on research and relevant theories. However, one carer stressed the danger of a medicalised perspective:

> *'…for example, you're looking for information about a condition, erm, I think that all aspects and all, erm, views on that condition should be included, so, er, you don't just get the medicalised version… so people can make their own mind up rather than having it dictated to them…' (Stella, carer interview)*

This carer argued that providing information from varying perspectives could promote carer autonomy. This is complementary to a person-centred approach, which allows carers to identify and utilise support they feel is suitable to their situation. Thus, participants reported a need for unbiased, balanced web-based information to increase knowledge regarding illness and available treatments. Whilst professionals noted the importance of hope promotion, one argued the importance of realistic, as opposed to, sanitised information:

> *'…most of the online presentation is that it's sanitised, there's always a positive outcome and if you read our partnership Trust website, you'd think that every little health problem was cured and that someone would come around and see you every other day if you were feeling a little bit iffy but*

actually, it's a devil of a scramble to get anybody to see anybody at all anywhere… one of the major things for me is that carers are not treated as intelligent human beings…' (Linda, professional interview)

Sanitised information could provide an unrealistic perspective of the health service and increase frustrations with healthcare professionals when expectations failed to be achieved.

"The world opened up": The value of knowledge

Participants noted that web-based information provided through websites or forums could increase knowledge. This was seen as particularly useful at the beginning of the caring role and could have a positive impact on a carer's emotional health:

'…there was someone on there that mentioned a book that I went ahead and read…which erm, you know, made a massive difference… it was like reading my life and all of a sudden the world opened up where other people know what I…was feeling and actually it was ok to feel like that…having that information… it makes a difference to being able to look after yourself and being able to understand that yeah it's alright to feel not very good because it's actually not very easy and so (laughs) it's not surprising that you don't feel very good or, you know, all the time, you can't always feel great' (Rosa, carer interview)

Further implications included reduced worrying, reassurance, hope promotion, increasing empowerment, confidence in coping ability and progress. Web-based blogs and interviews also provided knowledge and understanding about schizophrenia and their relative's experiences:

'…I've also been able to go online by the way and, and see interviews with other people who have schizophrenia… I must have seen dozens of those…quite, quite interesting…' (Eddie, carer interview)

This increased understanding could result in more patience and influence communication and response to their ill relative. Relating to EE, this could impact on care recipient health and prevent relapse.

The below professional noted the value of knowledge on carer and care recipient health:

'…if we can get good quality information out there about psychosis, balanced information… people will think "Whoa like I've actually, you know, I can, I can beat this, I'm going to be alright you know like"… and carers will feel that as well…I focussed very much there on like how a carer's point of view influences the patient's recovery but the other side of it is I suppose is that, you know, as a carer, your quality of life is probably going to improve as well

isn't it?… you're going to be less worried about them if you think they have a chance of getting better…' (Lee, professional interview)

Web-based information could impact on management of the caring role and treatment of schizophrenia:

> *'…people do go away and read all these factsheets, they definitely do and when we see them next or talk to them next, they always say how useful they found all the online information… I've had people who said that they've read factsheets about responding to unusual behaviour and have had change how they communicate with someone and it's helped…' (Chloe, professional interview)*

> *'…I also learned quite a bit about different medications and I was able to suggest to his consultant…that he change to this or that, or reduce this and that and we could discuss it… and I was able to say, "look let's try this" and er I got information online." (Eddie, carer interview)*

As can be seen, the knowledge acquired from web-based resources can impact on the care recipient's treatment and promote collaboration with healthcare professionals. However, whilst there was an assumption that empowerment could promote carer health, this may not be the case:

> *'…not sure they make me feel any better with actually dealing with the situation but… I don't know if I feel any better but I know I'm better, I think I'm better equipped, you know, marginally…' (Lynn, carer interview)*

Summary

The relationship between the four subthemes was presented in Figure 4.3. Carers reported a needs-based search for web-based information, in particular relating to responding to situations encountered within the caring role. Carers suggested topics for inclusion within the web-based intervention, based on the perception of meeting a need-based approach. One example of this could be practical information regarding legal rights.

Receipt of information for the suggested topics could have a beneficial impact on carer health. For instance, increasing management of the caring role by providing reminders of appointments or increasing carer knowledge of schizophrenia. There was an assumption that information provision could increase empowerment and hope. However, receipt of harmful or false information could have negative implications. This could increase fear of the care recipient, which could impact communications and create delays accessing treatment or support.

4.4.3 Theme 3: Connection, understanding and advice online

The third theme, connection, understanding and advice online, is defined as carers' search for peer support to receive understanding from those with similar experiences. This also refers to the need to humanise web-based support to encourage usage and adherence.

This theme includes four subthemes;

- "I'm not alone": Seeking understanding.
- "All in the same boat": The difficulties with web-based peer support.
- Moderation.
- Humanising web-based support.

The relationship between these subthemes is illustrated in Figure 4.4, following which the subthemes are defined and explained.

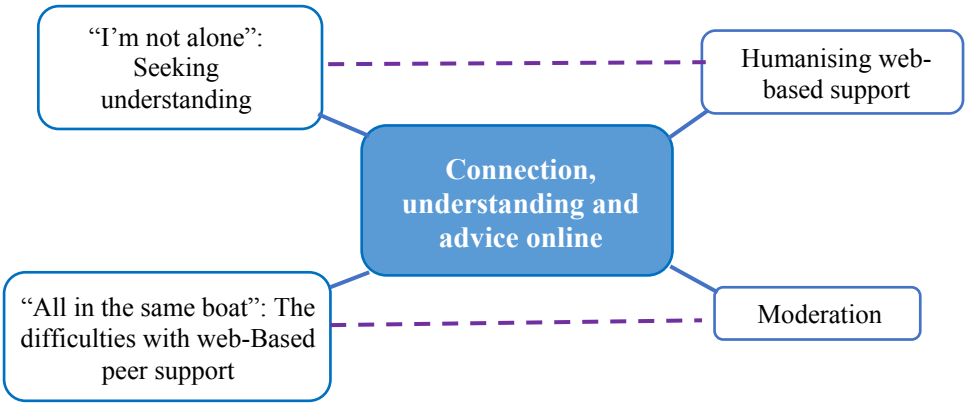

Figure 4.4. A visual depiction of connection, understanding and advice online and the relationships between the subthemes.

"I'm not alone": Seeking understanding

Carer isolation was noted at the beginning of the caring role but also experienced throughout. Only one carer reported lack of familial support and receiving judgment:

> *'…you find that people judge you, you kind of almost get used to people sort of making really kind of stupid remarks… things like "Ee you've got no life, have you?" Well, well yeah I do have a life, it just doesn't happen to be the one you've got… at least you don't have stupid remarks… from an online app…' (Maria, carer interview)*

Despite this, the majority of professionals noted the continued stigma of mental illness:

'...because often erm the carers we support say that we don't feel able to either talk to friends and relatives about erm, or colleagues about their situation but if they know somebody else that's in a similar situation, they feel more comfortable to talk to them and discuss things whether it's about their loved one or whether it's about how they are feeling...' (Ella, professional interview)

'I find that because of the stigma, a lot of people don't speak out about it because it can be a more isolating experience being a carer of someone with a mental illness, especially a severe mental illness as there's a lot of misunderstanding out there ... a lady... she wasn't able to tell people at work why, she had to lie and make up a reason, because she didn't want to tell people at work that her son had a mental illness, if her son had leukaemia, she would be able to tell people...' (Chloe, professional interview)

During the member-checking process, one professional suggested that stigma may continue to prevent use of web-based forums. However they later acknowledged that this may be influenced by other disclosures. Peer support was reported to reduce isolation, frustration and powerlessness. In some cases, this was preferred over other forms of support:

'...we ran... courses... getting a group of carers together in a room... usually what happens in the first session is people cry and by that third session they all know each other's life histories... one of the things that always emerges quite quickly is that sense of having been completely on their own with this, often for 20 years, 30 years erm and having had very little support either from the rest of the family or neighbours who have not been close enough to really understand what's going on so they kind of backed off or taken a very judgemental role... so what happens is that families become increasingly isolated and when they're actually in the room with other people who do understand, it tends to be quite a sort of cathartic experience and... there's a lot of comments when we do our evaluation at the end of the course that people have found that the most helpful thing, I mean... [we] can stand up and say anything really as long as the people are together (chuckles), in the room talking to each other...' (Linda, professional interview)

Carers considered peer support useful:

'...I've heard people talk very dispassionately about somethings which could probably shock other people completely and, but if you're given that kind of arena to speak quite openly, I think it's really helpful to carers...' (Heather, carer interview)

Whilst the above quotes focus on non-web-based resources, this could also relate to web-based forums. Half of the carer sample reported accessing web-based forums for support. Peer support was credited for reducing isolation and encouraging sharing of experiences and advice to overcome problems. Although peer support with other carers was noted to

be useful, interaction with mental health carers was praised as providing understanding without explanation. This carer illustrated further advantages:

> *'Realising that others share my thoughts + feelings – I am not alone.' (Rosa, carer diary, week one)*
>
> *People understand that frequent contact is not always possible or advisable so helps with the sense of guilt (Rosa, carer diary, week 2)*

For introverted carers, the web-based format provided the ability to lurk; the ability to view posts and conversations without needing to contribute:

> *'I didn't really fully understand how to use it or the cost of using it so it was more accessing it and looking at other people's posts… rather than being able to communicate confidently at the time.' (Rosa, carer interview)*

Some carers appeared uncertain about web-based forums and did not use these as a form of support:

> *'…I mean I haven't gone onto any of the forums things because I've never really, although I use Facebook…and use the internet quite a lot, I'm not on, and I go to a carer's group, physically go to a carers group… I don't tend to join forums so I'm discussing with other people online, I might look at what other people have written… I think you need to be a certain kind of personality perhaps to share a lot, I don't know.' (Lynn, carer interview)*

The above quote highlights the preference for non-web-based resources accessed via local carer organisations. There remained uncertainty regarding whether the same benefits could be provided via the internet due to limited human contact. Regardless of this, web-based resources could remain useful for accessing information without the need to contribute.

Professionals encouraged peer support use, reporting that this could improve carer health and influence the care recipient's health as a result. Sharing advice could promote empowerment and feelings of control over the situation. Longer-term carers could be seen as being more experienced than healthcare professionals and the internet could provide the opportunity for knowledge exchange. Thus, this could provide a voice to carers that may otherwise be unavailable.

Web-based resources could provide access to discussions that may otherwise be unavailable:

> *'…read about "Oh there's this, there's a discussion about psychosis treatment options happening at four o'clock on Thursday afternoon et at this web address"… people could just drop into that… you could maybe choose how you wanted to interact with it, if you just wanted to observe it and not interact*

then you could do that… or if you wanted to be a participant in it and like actually share your experience or views or ask questions then maybe you could do that as well…' (Lee, professional interview)

There was a debate regarding the effectiveness of web-based peer support compared to non-web-based peer support:

'I don't know if you can duplicate that online because again because I've not grown up with that sort of online presence… I automatically distrust… anybody who's posted a comment online, whereas if I meet somebody face-to-face in the same room, I feel much more able to, erm pass judgement on whether or not they're having me on or deliberately lying or whatever, so I'm not sure if an online forum would provide quite the same sense of, erm, being able to share and that reduction in isolation…' (Linda, professional interview)

'I think erm having a forum… where people could talk to each other erm or we really encourage peer support in our service so when we're not available or the service is not open or the groups aren't running, people can link up with each other, and… maybe have a coffee or meet or just have a chat about you know, general chat, it doesn't have to be about the person they are supporting so I think a forum would help in that way as well, you know, because often erm the carers that we support say that we don't feel able to either talk to friends and relatives about erm, or colleagues about their situation but if they know somebody else that's in a similar situation, they feel more comfortable to talk to them and discuss things…' (Ella, professional interview)

One professional queried the quality of the web-based relationships:

'…many carers are isolated and feel they're alone in shouldering the burden that they've got erm so it can break down some of that isolation, erm improve people's connectivity… erm so they're less, less socially isolated, it doesn't necessarily affect their loneliness because that more depends on the quality of those connections…' (Jim, professional interview)

The above quote questions the difference between connectedness and loneliness. For instance, whilst web-based resources could create connections with carers, this may not affect isolation. Professionals discussed the availability of web-based forums, such as Rethink or Facebook groups, however they were uncertain regarding the use of these by carers. Interestingly, one carer reported previous use of the Rethink forum but stated that this was no longer available. This could indicate the continued change regarding resources and lack of financial funding.

This professional also queried the value of forums for present issues:

'…there tends to be more people who are recounting things in, in retrospect… than in the here and now… Erm you tend to get lots of people saying, "wasn't it terrible," you know "do you remember…" And lots of people going "Oh

> *yeah that was terrible, I can imagine that was really bad"…' (Jim, professional interview)*

Whilst this could be beneficial in aiding the development of rapport and relationships, it may suggest there can be a limited focus or lack of debate regarding current situations.

Web-based peer support was often linked to social media use. Carers reported using social media and web-based forums, however there did not appear to be a direct relationship between the two platforms. For instance, carers reported using web-based forums and not social media or vice versa. One suggestion for this relationship could be the increasing popularity of social media as a communication method opposed to the traditional chat room session.

This carer described the creation of a web-based forum:

> *'…I couldn't find one [chatroom/forum] that was strictly for carers, in fact what happened was I was in a, I was on a site for schizophrenia, hoping to get some advice from people, hoping to…share experiences, and people with schizophrenia kept posting comments… a lot of people with schizophrenia talk complete and utter rubbish… in fact we were getting no, nowhere so I started a site just for carers…' (Eddie, carer interview)*

As can be seen, this carer reported limited web-based forums for carers of an individual with schizophrenia. This resulted in this carer creating a form of web-based support to fill this need. There was reported difficulty in ensuring carer-only access to this resource:

> *'I've got a couple of people with schizophrenia on there but if anybody starts talking nonsense then er they're out of it altogether…' (Eddie, carer interview)*

The comments posted by individuals with schizophrenia could be distressing for carers and could suggested limited privacy using web-based support. Alternatively, if carers posted during a stressful period, it was likely to be emotive and therefore impact upon the individual with schizophrenia who may see the post. Despite this, one carer noted that this perception could be useful:

> *'…this gives an insight without having to question my son…' (Rosa, carer diary, week 5)*

Humanising web-based support

The importance of humanising online support was raised within professional interviews:

> *'…if it's really personal so this idea that we're talking about highly personal emotive and distressing or a potentially distressing subject, if it's presented,*

erm if it hasn't got that human touch or it doesn't feel responsive or erm, I think there's a risk, again there will be a risk that that would turn people off…' (Lee, professional interview)

Web-based resources were criticised for a lack of personalisation to the carer's current situation, resulting in a need for carers to relate information to their situation, which may be difficult. This impersonal nature could reduce web-based support use, therefore failing to have an impact on carer and, as a result, care recipient health. This could influence the professional's opinion of web-based resources and subsequent recommendations for use:

'…sometimes to say there's an online thing, it just feels a little bit, yeah you know what I mean? It's not as human… sometimes people might, I mean the reaction of this one guy when I did try was exactly what I thought it would be…' (Chloe, professional interview)

There was a suggestion that by humanising support, this would promote use and be relatable to the carer. The below quote provides some suggestions to overcome this issue:

'…the nature of the medium is that it is er it's robotic and it's not like erm it's not as a person is sitting in front of you, I suppose the ways that I would do it are things like, like literally having a human voice so like a video or something, where someone was talking about their experiences… I think sometimes things like podcasts and things like that are really, are a good erm way of sharing things, they can be really personal, you know it's quite intimate, someone talking in your head…' (Lee, professional interview)

The promotion of a conversational tone and ability for a web-based resource to continually develop and be updated was suggested by participants, and this could refer to the creation of an online community. This reiterates carer reports of isolation, loneliness and the need for peer support, but could also promote the need for human contact, which may be difficult to achieve via technology. Advancements in technology could overcome this issue:

'…with today's technology you can, you know, if you, if you want to use Skype or erm FaceTime, you know, so it's not like you're sort of talking or, you know, something that you can't, you can't see the person…' (Ella, professional interview)

This may help overcome the impersonal nature of online support and again promote usage and effect on carer health. However, there remained debate regarding whether humanisation of technology could be achieved:

'…there's something paradoxical in there as well… about many carers you know saying they want someone to speak to, they want, they value the human support… but if that human support is coming through a digital interface, is it still human?… Does it feel human? I mean it is obviously but I mean, does, does it actually feel human?' (Jim, professional interview)

Despite this, one carer noted the advantage of a remote access to support:

> *'...you do have your ups and downs and when you're on a down, you're not always up to that so I think, you know, meeting people online... is a, is a way of staying in touch without having to go out and face people... online if you're getting teary nobody knows about it do they?' (Rosa, carer interview)*

This suggests the internet could almost be used as a shield and provide security and privacy for those feeling vulnerable.

"All in the same boat": The difficulties with web-based peer support

Despite the benefits of internet forums, carers and professionals noted problems with web-based support. For instance, participants noted the potential for negativity via web-based forums:

> *'...there are people who won't come because they say they don't want to hear other people's, they've got enough, if I may be technical [laughs], they've got enough shit in their own life without listening to other people's...' (Linda, professional interview)*

> *'...we have had some carers that have sort of, sort of erm accessed Facebook and certain sites, er there's one, I think there is one for schizophrenia and one of the carers just said "I just felt so negative when I'd been on the site... erm because of the feedback that I got and it just made me feel that there's no hope for the future" and so I think that would be really bad... for the person, for the carer's wellbeing.' (Ella, professional interview)*

> *'...I find in fact that we're all in the same boat...nobody's given any, we're all complaining, we're all desperate, er we're all dealing with it best we can...' (Eddie, carer interview)*

There was also the possibility of receiving emotive responses via web-based forums. For instance, distress could be projected onto responses and could therefore influence perceived usefulness of the forum, carer hopelessness and willingness to contribute. Professionals acknowledged that this could occur in organisational-supported and external forums (such as those on social media).

This carer noted the comparison of their situation with other carers:

> *'Many relatives are living with the ill person so sometimes I feel guilty that mine does not live with me.' (Rosa, carer diary, week 6).*

Further examples included comparison of available support with other areas and living situations.

Professionals were more likely to raise concerns regarding the use of web-based resources. For instance, the risk of over disclosure was discussed:

> *'...you don't have any control over what people say to each other... I know organisations are a little bit terrified about that... it's all about setting boundaries and a lot people that are vulnerable and upset and have got crisis in their lives don't, might struggle with barriers sometimes... you know going into microscopic detail you know about someone's self-harm... it can be extremely triggering...' (Chloe, professional interview)*

Over disclosure could result in carers sharing personal and identifying details regarding themselves and their own needs or the care recipient. As the above quote illustrates, this could also be distressing for viewers. The popularity and availability of web-based resources also increased this risk:

> *'...if you've got an online support group, you can cut and paste and thousands and thousands of people can see it in seconds, whereas if it's a support group someone says someone, they might tell a couple of people maybe, I mean I hope they don't but I'm sure people do, like what they heard, erm but there's less risk there...' (Chloe, professional interview)*

Whilst a concerning post can be removed from the forum, the possibility of screenshots and digital footprints can prolong availability of content. One participant illustrated the importance of ensuring confidentiality when using web-based resources, suggesting that there would need to be reassurances to promote usage:

> *'...if there was like a psychosis or whatever Facebook group... I would like have it private or... something like that so people could be members and access information but it wasn't like advertised on their profile that they were part of it, just so it respected their privacy and maybe the need for discretion about it, about the subject...' (Lee, professional interview)*

Professionals identified risks of sharing inappropriate advice on web-based forums:

> *'...I think that could maybe be a bit of a danger with online support if it was like erm a forum for instance a peer forum, it could maybe somebody might say "I think maybe you should do A, B, and C" but that could totally be the wrong thing for that person...' (Ella, professional interview)*

As carers may not have previous healthcare training or awareness in judging the quality of resources, there is a risk of the distribution of negative or inaccurate information. If this information influences behaviour in the caring role, it could negatively impact carer and care recipient health. Another concern related to the ability to convey messages online:

> *'...I think online there is the, the risk of, well you see it on Twitter, on Facebook... you can quite often express things in a way that can be*

misunderstood… or people can project onto things, certain meanings that may not necessarily be intended… and things can get a bit oppositional as well… it's like the tweet you never see sent is someone going "You're absolutely right, you've changed my thinking on this"… is more like a debate er with one side you know, and people thinking "I will win" or "you will win"…' (Jim, professional interview)

Further contributory factors to misunderstanding included the lack of facial cues, which can usually aid interpretation of intent. This could also be affected by literacy levels, particularly the carer's ability to read and communicate in an understandable manner. This professional also noted the difference in individual online identity:

'…there's always a bit performative about putting stuff online… when they're, they're conversing online… and things tend to get a bit kind of declamatory or putting of things on display…' (Jim, professional interview)

Participants also raised the potential of disagreements or conflicting perspectives on web-based resources:

'So you may sometimes get a response that you think "hang on, not quite sure about"… I haven't found that to be a big issue but I've seen sort of discussions that have developed where people have perhaps, you know, felt unhappy with the response they've got…' (Rosa, carer interview)

However, one participant did not see this to be a problem:

'I personally, human beings are human beings, I think er that people are going to be alright, I don't honestly think there will be a huge amount of abuse… from carers… I can't see it happening.' (Robert, professional interview)

Negative elements of web-based support are important to consider as failure to overcome these can affect usage and engagement in interventions.

Moderation

Moderation was an important element to be included within a web-based intervention and could overcome negative implications and protect users. This carer noted the value of moderation:

'I think it's a general rule anyways… keeping an eye on, on the communication, make sure that people aren't getting wound up or a bit too argumentative or posting things that are going to be offensive… that's the last thing people, any of us need, is to have to deal with that sort of stuff when you're struggling already…' (Rosa, carer interview)

Moderation largely focused on that provided by professionals, and could reduce possible misunderstandings, edit inappropriate responses, or provide advice. However, this could

reflect the traditional balance of power, with professional moderation placing them at a more powerful position than carers.

Despite this, professionals noted difficulties with moderation:

> *'…moderating chatrooms actually increase the cost of things… you need to have a live moderator to… run it, the other way of doing it is for things to be delayed so that people can kind of put in stuff and then someone looks at it, once a week and then… puts it into the chatroom, so there's a bit of delay but essentially there's moderation and there's confidentiality and stuff like that… live moderation that it increases cost, yeah because there's someone having to be paid to keep an eye on things unless there's kind of volunteers who can do that… if someone is, goes over, over the line I think that other people would just remind them… I think it's sort of self-moderating.' (Robert, professional interview)*

The below quote identifies a possible solution:

> *'I think you could moderate them to a degree, you would have to have a face-to-face assessment with someone, make sure they're OK and then join them up to the support group… it would be fine but you would have to moderate it so yeah I think that is a, is it just easier to meet or…?' (Chloe, professional interview)*

However, this could increase the required resources and create delays in accessing the web-based resource. Further considerations could consist of a preference for non-web-based resources and service involvement (further considered later in this chapter).

Summary

Figure 4.4 presents the two key relationships between the four subthemes in connection, understanding and advice online. Participants noted that carers experience isolation and value sharing experiences with others in similar situations. The remoteness of web-based forums can make it difficult to achieve human connection. Whilst some individuals feel this can be achieved via web-chats, others proposed the use of Skype or video chat.

Participants discussed the difficulties with web-based peer support, for instance negativity, comparison of situations and over disclosure. These difficulties could be reduced with the use of a moderation service. However, this can create barriers such as available resources and the ability to provide a live service.

4.4.4 Theme 4: Personal preference: Considering the accessibility of the internet

The fourth theme is defined as the consideration of the increasing accessibility and permanence of web-based resources with acknowledgement of the barriers towards usage. This theme is further defined as the recognition of accessibility on carer personal preference for support.

This theme includes six subthemes;

- 'Tapping in on the bus': The accessibility and availability of the internet.
- 'Different for every person': Person-centred support.
- A permanent safety net.
- Digital literacy.
- 'Dry bowl of muesli': The presentation and tone of information.
- Other barriers to access.

Figure 4.5 presents the relationships between each subtheme. Attention then moves to the presentation and explanation of the six subthemes.

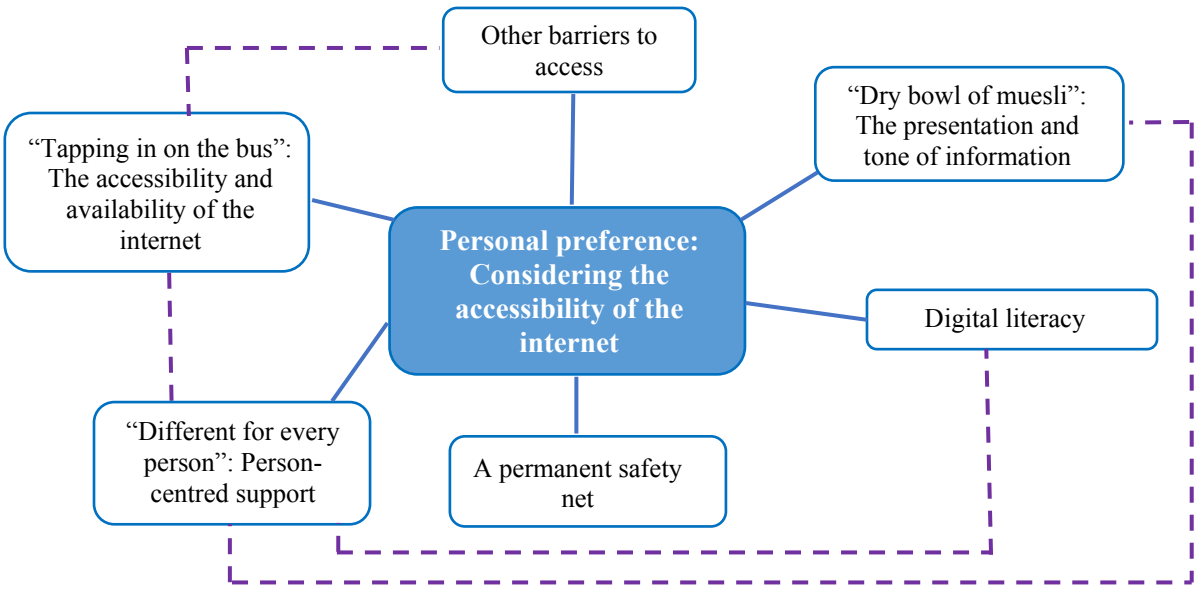

Figure 4.5. A visual depiction of personal preference: considering the accessibility of the internet and the relationship between subthemes.

"Tapping in on the bus": The accessibility and availability of the internet

Participants commented on the availability and accessibility of the internet and web-based resources through multiple devices. For instance, the introduction of smartphones had enabled access to web-based information and resources. Participants credited web-based resources for providing support for those who are unable to access non-web-based support:

> *'…they won't have to make an appointment, they can just use it, it's there, it's accessible erm as as when they need it or, you know, it will really fit in, especially carers that work or have really busy lives or other commitments that don't always erm have the time or able to fit in erm either going to groups or accessing er face-to-face support…' (Ella, professional interview)*

Carers discussed the value of accessing resources out-of-hours:

> *'…if you feeling rubbish at 4 in the morning, you can go on there and… you might be able to, you know, er find something that's helpful… because, you know, anything else you've got to wait haven't you?' (Rosa, carer interview)*

> *'… there's very few places that you can ring up at 3 in the morning and say "help I'm having a shit time", you know so online support would, is a really good tool for that, you know it, it gives you, it gives you quick accessibility.' (Maria, carer interview)*

These quotes suggest that web-based resources could provide support for carers in full-time employment. This form of support could also be advantageous for individuals who are housebound or unable to travel to external locations. Despite this, it is important to note that some web-based resources do not provide instantaneous access.

> *'Erm well I signed up for a course that they're doing but it doesn't start until October…' (Penny, carer interview)*

This professional credited smartphones for continuing to facilitate access to web-based resources:

> *'…I guess we've not talked about apps, that would be quite useful (laughs)… having like a mobile phone app, erm I suppose that's because people are on their phones all the time and actually that's quite private isn't it?... So if the intervention could be something on an app on your phone that can be tapped into when you're on the bus or something like that, that might be actually really useful, talking about it, that's something that I could fully, yeah get behind…' (Chloe, professional interview)*

Discussions regarding web-based support for carers largely focused on accessibility via a computer, with smartphones considered as an afterthought. As can be seen from the

above quote, this professional was positive about the use of smartphones in providing web-based resources, attributing this with privacy and increased accessibility. Consequently, participants considered information was more accessible to users and professionals noted that this had been often been accessed prior to seeking support through an organisation. However, some carers reported being unaware of available resources such as web-based courses:

> *'... I've signed up for the online course on schizophrenia but it doesn't start until the 9th October… and I didn't know about that, I have to say I learned about that from you so you've done some good there…' (Eddie, carer interview).*

This indicates that lack of knowledge regarding available resources could prevent access to web-based support and information.

"Dry bowl of muesli": The presentation and tone of information

Participants described difficulty engaging in web-based resources that contained too much information:

> *'...it's just massive, it's like a bowl of dry muesli in terms of like how much information there is, there's just tons and tons and tons of written text, there's a few pictures, there's a few videos but it's like really, really like wordy and deep… I feel like a lot of carers or service users that I point towards that will take one look at it and think "Oh I'll read this another time" and then they never go back to it because it's just information overload…' (Lee, professional interview)*

> *'...I've only ever looked at things for maybe 10-15 minutes… at a time, erm because if you're looking at too much of it, it can become a bit too much too much to cope with… I just find that looking at too much information at once… you just start not reading it…' (Penny, carer interview)*

Too much information could affect carer adherence, suggesting that carers may be unable to access potentially valuable information. Alternatively, this could provide information regarding a range of situations that may not be relevant to the carer's situation. One carer considered the impact of information as surplus during their relative's initial diagnosis:

> *'... I would now probably think that there should be more information at first diagnosis… but I think you've got to be really careful about that… it's actually quite a frightening experience for everybody involved and perhaps at first diagnosis, there is, would be a danger of having too much information… there is… an actual physical package which is provided by the local mental health trust which has some background information… looking back on it… from my position sort of 10 years down the line, I thought 'oh there's not enough*

information in there', but then if you can try and put yourself in the position of somebody who has just had somebody diagnosed… you want the information which is really relevant to you at that point, you don't want to be frightened to death by so many things that are might happen or might not happen down the line…' (Heather, carer interview)

The above quote highlights the delicate balance required in providing information to carers of individuals with an SMI. Whilst information provision could have beneficial impacts on the carer's management of the caring role and their emotional health, surplus information could increase carer distress. Participants further indicated a balance between transparency of knowledge regarding the condition and the presentation of this. Although transparency of the situation was considered important, there was a concern that this could increase fear or distress:

'…how do you pitch it, like what's the tone of this type of information?… How do you make it, erm oh what's the word? Like balanced… you're talking about the good stuff and the bad stuff because we've got to be realistic… some people unfortunately don't get better from psychosis, or at least you know they might need to stay on medication for a long long period of time, or they may have residual symptoms for a long, long period of time, how do we be balanced about it but without being scary?' (Lee, professional interview)

One suggestion to overcome this issue included the presentation of information in brief sections. This professional provided an example:

'…maybe have drop boxes like with, erm, you know, erm, different types of illnesses that someone can click on and then… it could be giving some hints of something, you know, what to do, almost a bit like mental health first aid…' (Ella, professional interview)

The choice of accessing further content could promote engagement with a web-based resource and allow carers to access more information depending on their situation and needs. One carer described the importance of this during a stressful situation:

'…when you're stressed or when you're stressed about the person who's caring for you, you cannot be doing with in-depth words, it's got to be simple, it's got to be snappy…and it's got to be colourful.' (Maria, carer interview)

Participants argued that information should be understandable and use lay terminology as opposed to medical terms. Carers may not have a medical background or may experience difficulty understanding information due to distress or literary ability. Failure to understand information could cause difficulties for carers and reduce any beneficial effect associated with these resources. Participants also noted the usefulness of images and videos in promoting engagement and increasing understanding:

'...I wonder if pictures would be a good idea?... Because they stand out... if you've got someone who's I guess got learning difficulties, they're going to... take more notice of a picture, they'll understand that more... and to be honest, I know if I'm presented with like an app, it's the picture that sort of hits me...' (Maria, carer interview)

"Different for every person": Person-centred support

This professional described directing carers to resources based on his appraisal of their needs

'...I suppose it's different for every person...for an older carer who's never like come across psychosis before and never even really thought about mental health...in terms of what might cause mental health problems... I would recommend one thing, whereas for a carer who's really tech savvy and is au fait...with certain principles of mental health like stress vulnerability and like psychological and social influences on mental health, I would recommend something totally different...at the minute I feel like I'm having to... signpost someone based on where I think they're at and part of that is that there's so many different sources and I would hate to signpost a carer to one particular source, knowing that there's a risk they would be put off accessing that...' (Lee, professional interview)

Therefore, there was a need to ensure that web-based resources could facilitate individual choice and contexts:

'...carers are going to come in all shapes and sizes and they're going to have different erm technical skills... they're going to have different preferences about how to like read about this type of material or engage with it... people like are going to want to watch a video... some people going to want to read er a long form thing for it, some people are going to want bullet points... so how do we create something that kind of hits all those marks, how do we create something that's really accessible for all range people...' (Lee, professional interview)

'...you would approach it looking for different things... I was looking for very sort of factual information... looking for help with a specific, er, problem... but somebody might have maybe time to do, erm, like a more in-depth, erm, like course, one of the caring courses...' (Stella, carer interview)

Presently, web-based resources appear to provide general support, such as delivering a range of information relating to one topic. This results in the carer attempting to locate content relevant to their situation and needs. Individual differences included personal factors relating to carers and their situational needs. There was an awareness that individuals learn via different methods and may have disabilities preventing engagement. Therefore participants argued that individual differences and needs should be considered within intervention construction. For example, this could include multiple formats for

information provision, such as written text and video, to increase engagement to a wide range of users. This could further indicate that users may not engage with resources if they are not displayed in a favoured or appropriate format.

Participants considered situational needs:

> *'…well there's two issues aren't there? There's the person who's supporting someone who hasn't been recognised or diagnosed as having a problem so you're going online to try and find out what the problem is, but if you assume you know what the diagnosis is… if they're not diagnosed, you're not sure exactly what you're dealing with and you have nobody on your side to start with, I mean once someone has been sectioned for example, they're in the system and in some ways it's easier then because they already have this network… there is a difference I think in erm someone who's in the system and someone who isn't in the system and someone who has been diagnosed and someone who hasn't been diagnosed.' (Lynn, carer interview)*

Further examples included; living arrangements, diagnosis (including whether this was received) and symptoms experienced by the care recipient. This could suggest the need to provide personalised support to carers in accordance to their situation and minimise the requirement of finding personalised information.

One carer argued the need to provide support to all family members:

> *'…it's a big bugbear of mine… I always campaign for any young person who is in a family where there is a family member who has a serious mental health problem erm to be considered a carer because they're impacted… they are very often overlooked…' (Heather, carer interview)*

This indicates that support is largely provided for the primary carer, despite suggestions that this can impact other family members. This further suggests that other family members may be assisting the primary carer in caring for an ill relative. The above quote focuses on younger family members who may have increased confidence in utilising digital devices.

This carer suggested a method for providing personalised support through a web-based resource:

> *'…when you get stressed, you're probably not likely notice what you think but you are going to notice what you feel… these are the feelings, this is what you do in response to them, and if you change the things that you do in response to them, and if you change the things that you do in response, then what happens to the feelings?… like an algorithm so this is, you know you feel this way… do you do this or this and click onto it and you've kind of got like an algorithm of what to do and at the bottom, it gives you ideas which would, could be kind of like personalised to you…' (Maria, carer interview)*

Whilst this quote originally referred to the acknowledgement and identification of needs, this was also used to highlight the ability of providing personalised support via an algorithm. The use of this could identify carer needs and refer the user to relevant content.

Another suggestion to promote person-centred support could be a multiplatform web-based intervention:

> *'...what do I expect... if I'm buying something online, er I can like click on a product and find out information about it, and if I want to know more… I can read an item description and if I want even more information I can read an item specification thing… which like goes into crazy technical detail and if I want to know how other people who bought the item get on I can read user reviews and if I want to know more information, I can watch like YouTube videos about the item, that's what I expect from mental health services … I want to be able to produce something that can be viewed on a range of platforms that have got good quality verifiable information, that's unbiased, practical, reliable, er well researched that has got like tiers of information so you start with super accessible bare bones but good quality stuff and if you want to know more you can read the item description equivalent, you know like here's some information on psychosis, if you want to know even more, you can go into the items specifications bit and read tons and tons and tons, if you want to know even more there's like user experiences, you know the equivalent of user reviews and stuff, carer reviews, carer opinion, carer experience, do you know what I mean?' (Lee, professional interview)*

Multiplatform support could also encompass multiple devices:

> *'...here's a real life example, here's a YouTube video featuring a carer talking about their experiences, erm download our app, it will help you with complicated buzzwords that you might hear from psychiatrists…' (Lee, professional interview)*

The use of multiple devices could continue to increase accessibility and autonomy for carers. This may also tailor support to the individual's personal preference:

> *'...I think it's also just people's person preference and what works for them, erm some people are happy talking on the telephone, some people are happy…describing their troubles in online…' (Jim, professional interview)*

The promotion of choice was noted to be important for web-based and non-web-based resources. Regarding web-based resources, carer choice was related to access and adherence to the resource. This participant highlighted the importance of clarity to encourage carer autonomy:

> *'Well I just think that if it's clearly labelled that these are carers stories than people can choose whether to read them or not… I've had people who's come along to groups and then said to me afterwards, "I'm not coming back, I can't listen to everyone else's stuff as well"… if it's clearly labelled… people have a choice and they're not sort of slipped into articles… when they're not coping*

very well, they're very vulnerable… it's very easy for them to be brought down by stories of other people's misery… they don't need that really on top of everything else' (Linda, professional interview)

However, participants acknowledged the difficulties with providing too much choice, as this could result in carers feeling overwhelmed and therefore affect engagement with the intervention:

'Diary question: What didn't you like about this [resource]?

Maria: Too many choices + needed to click on other bits of information which made it difficult to get information in one go.' (Maria, carer diary, week one)

A permanent safety net

One carer reported that web-based resources were a permanent source of support. However, others noted that this was incorrect and cited resources that were no longer available. One example was Rethink, a web-based forum, which one carer reported was no longer available, while a professional suggested this as an available resource. Despite this, the ability to download information could promote permanence:

'…I have got about 10 screengrabs of notes from a lecture, er I must have been impressed with it… it would have been about 6 years ago and I've still got them because I found them the other day.' (Eddie, carer interview).

This suggests access to content can remain even if the original source was no longer available. Whilst this could be beneficial for carers, it may raise concerns with the use of outdated information and support.

The permanence of web-based resources was further achieved by the ability to revisit resources:

'I went back to the fact sheets and found three of interest' (Eddie, carer diary, week five)

Carers viewed access to web-based resources as a safety net:

'So having information to hand when you think "Oh that's something that we're going to need to find out about, hadn't anticipated that, but I know where we could probably go immediately to see if there's any information about it there"…' (Heather, carer interview)

'…it's feeling that there's somewhere else to go… if everything has been tried, all the treatment, all the medication and you're still kind of struggling along, erm, sometimes you feel very alone… and you feel kind of "uh this is it forever now, there's nothing we can do…" (Stella, carer interview)

'I will be able to download info + look at this site again – reassuring' (Penny, carer diary, week six)

These quotes indicate that web-based resources could positively influence carers' perceptions of control and empowerment in management of the caring role.

Digital literacy

Carers reported that information could be easy to locate but may vary between devices. These carers described the difficulty of finding relevant information via a website:

'...there's some fantastic information out there but you have to scroll down and sometimes you, you kind of go into a bit of information and then you have to click on another link so you're literally clicking on about 7 links and if you're feeling stressed anyway, that doesn't help… it becomes unhelpful erm and quite often at that point you just think "Oh sod it" and just put it down…' (Maria carer interview)

'The sheets are in alphabetical order but this does not always help when searching unless your search involves the first word in the title.' (Eddie, carer diary, week four).

Carers praised easy-to-use websites, particularly when encountering a stressful situation. The entire sample emphasised the importance of a well-designed, easy-to-use intervention. This professional detailed the impact of poorly-designed interventions:

'...some people will get frustrated because they go "well I have queries or questions which I can't find, well what do you mean by that question?... I'm not really sure what that means" and if the help isn't readily available… if they're not quite getting the point of something is, well what they're meant to be doing…' (Jim, professional interview)

This indicated the importance of intervention usability and the ability to meet carer need. Despite this, participants identified general difficulties in using technology and the importance of technological literacy:

'…I'd say a quarter of our people that couldn't, that er wouldn't have an email address, so I'm guessing aren't computer literate…' (Chloe, professional interview)

'Internet is an expanding medium like the Universe. You need the experience and the knowledge how and what to search.' (Brian, carer interview)

This occurred regardless of experience with technology:

'...there was some instructions… and I don't know if I was being a bit slow but… it didn't really help massively… I do use computers a lot… and I go

online a lot, it's not that I'm completely useless on computers, but I didn't find it particularly helped me massively…' (Rosa, carer interview).

Participants reported that carers might lack digital literacy, especially if they have limited experience through employment. However, the above quote suggests that carers may also experience difficulties using web-based resources regardless of technological skill. This could indicate that difficulty using resources may increase frustration regardless of perceived usefulness. Additionally, there was an assumption that this could influence technology use and literacy:

'Younger generations are willing to seek more help online. This is because they are more familiar about [the] Internet. Texting, social sites like Facebook and other sites like chat channels creates all the differences. It is part of their life.' (Brian, carer interview)

'…well probably carers of a certain age… probably younger carers, people who are much more likely to be using their phones… as a regular support that would be much more useful, for people like myself… they're the kind of people who are getting on with their lives, dealing with things on a regular basis but don't sit and look at their phones all the time…' (Heather, carer interview)

These quotes suggest that younger carers were seen to be more likely to access web-based support. Participants noted that younger generations had more means of access, more technological literacy and were more likely to find web-based resources useful. There was also an assumption that younger people were likely to already be using web-based resources for support. Older carers were seen as having less technological knowledge and being less likely to use web-based resources. This is interesting given the age of the present carer sample, most of whom were technological users.

However, one professional suggested age may not be linked with technological literacy:

'…I don't always think it's an age thing, people often assume that older people find it difficult to erm to use, you know, use technology or, but I don't, in our service, we found, we found it's not not just the older sort of generation…' (Ella, professional interview)

This could indicate a requirement for training to facilitate technological usage. For example, support provided as a paper-based handbook or web-based training sessions.

'I know in the training that we had [information sharing seminar], erm, the booklet was really useful and very useful to take away. I mean it was really well presented… visually, you need something which is visual… and not lots of words and that was nice visual, this is what you're going to get on the screen and this is where it will lead you to, that was very useful and to be able to take that away and to go through it… but perhaps other people might need a bit of training, just to talk it through with somebody when they're first given that booklet…' (Heather, carer interview)

'...that's something which could be explored is a kind of handbook for people who are carers about online support, you know, how can you use it? What's available? How do you make the most of it?... Because I've not even asked the question before...' (Lynn, carer interview)

Other barriers to access

Despite the assumption of technological access, participants noted five further barriers to web-based support usage. One barrier was financial restraints:

'...I think this actually applies to lots of people on lower income... there's a lesser likelihood that people will have the highest and newest phones... so you get various restrictions as to, you know, what version of software that they've got, what version of Android or iOS erm they're on and how much storage and memory they've got...' (Jim, professional interview)

Whilst carers may have a technological device this may not be the latest model, which may, in turn, influence the accessibility of support or how this operates. This indicates that access to web-based resources may reduce over time in accordance with technological updates, preventing access via an older device. This professional described a possible solution:

'...some people might not be able to access computers ... but that sort of thing that can be easily sort out through like the carer's direct payment, if it was something that became more and more common then it could be that when a carer gets a carer's assessment, you know, you can buy a tablet for £80 which could be bought with the carer's direct payment...' (Chloe, professional interview)

A second barrier was the decision not to purchase technology:

'...because I don't have a computer... I rely on going to my local library... which I haven't been able to do very much in the past few weeks...' (Penny, carer interview)

Despite not owning a computer, Penny overcame this barrier by accessing devices at a local institution. When asked whether she would consider purchasing a computer, this participant noted that she was happy with her current process of accessing web-based resources.

Further barriers to accessing information included prevention by the care recipient:

'To join they wanted to[o] much information and my son insists that I remain anonymous so I could not progress very far.' (Eddie, carer diary, week 2)

'...I would say there would be a small percentage of people that might get, that might not be able to do it because the cared for might be wandering

around and checking their internet use and things like that…' (Chloe, professional interview)

This prevention could be the result of symptoms such as paranoia or hallucinations. Alternatively, this could include concerns regarding privacy, stigma and the possibility of being identifiable. This professional noted the consequence of a sign-up process with privacy concerns:

'…if you've got to sign up for something or it's got like a really high barrier of entry, like erm some of the websites I've seen, you've got to provide loads of personal information, erm I think that would be a barrier to entry and people would be put off by that…' (Lee, professional interview)

This could increase stress when attempting to access support. Carers may also be reluctant to provide identifiable information due to concerns of stigma. Not only could this deter initial use, but it could also influence further access if a login process was required for each visit.

Finally, a significant barrier to the access of web-based resources was time:

'Researcher:…[are] there any factors that really prevented you from using this?

Heather: Time [laughs]…that's why I was saying I'm probably not a very good subject at the moment because I haven't the time. But if I had the need… I would do it, I would find the time… if there was a change or if there erm was a situation where I thought "well actually I could do with having some information here before I go out… and look for other things as well", then I would find the time to use it..'

'…there will be a significant number of people for whom they don't have the, the erm opportunity to put in the dedicated time at home… they don't the opportunity to practise the discipline…' (Jim, professional interview)

'So I was looking for help with that but somebody might have maybe time to do… one of the caring courses and that might give them a greater insight into how to help cope…' (Stella, carer interview)

Carers noted the difficulty assigning time to search for web-based resources, despite holding an assumption that better quality information could be available. Difficulty finding time could relate to carer autonomy and lack of external influencers, such as professional encouragement.

Summary

The accessibility and availability of the internet can be dependent on overcoming barriers. For instance, financial restraints may prohibit access to web-based resources, in particular with the continued expansion of technology requiring up-to-date devices to ensure compatibility. Further barriers relating to financial restraints include the ability to keep up-to-date with software and informational upgrades. Despite this, participants suggested that web-based access is related to the carers' personal choice, for instance the preference for PC or mobile phone as a medium for support. This could also relate to the choice to engage with web-based resources as opposed to non-web-based support.

Within the subtheme "dry bowl of muesli", the presentation and tone of information highlighted the impact of information surplus on carer engagement. Information overload could reduce engagement with the web-based resource, and as a result prevent any health effects. One suggestion to overcome this could be the provision of information in tiers with the ability to access further content.

Finally, digital literacy can influence the accessibility and availability of web-based resources. Difficulty using web-based resources could impact adherence and engagement. Personal factors, such as age or previous experience with technology, could influence choice of access.

The relationship between subthemes are depicted in Figure 4.5.

4.4.5 Theme 5: The landscape of carer support

The landscape of carer support is defined as the consideration of available web-based and non-web-based support and resources for carers. This theme includes carer appraisal of, and the expected evolution towards, web-based interventions.

There were four subthemes related to this theme;

- The appraisal of web-based support.
- 'Bang for buck': The lack of support and resources.
- 'Evolution will take its course': The expectation of change.
- Service involvement.

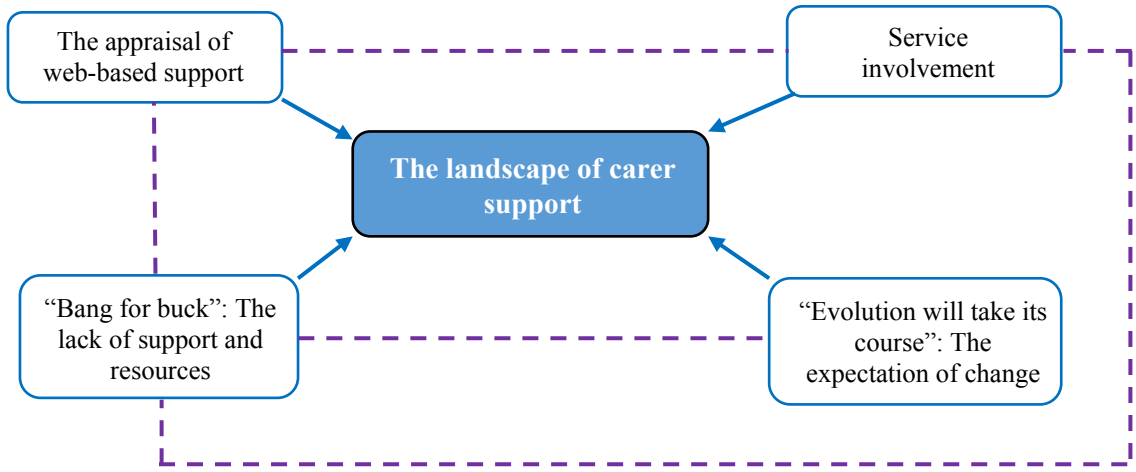

Figure 4.6. A visual depiction of the landscape of carer support and the relationship between subthemes.

The above figure depicts the relationship between the four subthemes, which are defined and described below.

"Evolution will take its course": The expectation of change

Carers and professionals noted the evolution of technology:

> *'…it used to just be that having a poster in the library or post office… now it's just going to be a shared image of a poster…' (Chloe, professional interview)*

The increased access to technology appears to be related to a view of a transition into a digital world. This has facilitated information sharing, thus impacting carer empowerment and control. Whilst there was a negative appraisal towards social media, this was credited for the ability to share information quickly and efficiently, thus increasing access to a range of carers.

One carer noted that web-based available information had improved following their initial search:

> *'…since our er first contact… I've found several that I haven't found before and I'm ashamed to say some of them have been going for a number of years and I've never used them… things did move on, but I wasn't aware of it.' (Eddie, carer interview)*

This could indicate the need for reminders or updates regarding available support for continued usage and to raise awareness. It could also be useful for long-term carers who may have difficulty becoming conversant of further developments.

The growth of technological usage was linked with age:

> *'I am sure that next generations will use all sorts of online interventions for their wellbeing and their social problems. Evolution will take its course' (Brian, carer interview)*

> *'…the world is more and more digital and you know, we've got digital natives coming through and adulthood now…' (Jim, professional interview)*

> *'…I think as new generations come through they are kind of that much more at home with using online resources than that problem will diminish so it's only a short term one really.' (Linda, professional interview)*

There was an expectation that younger generations were more likely to use web-based resources. Participants predicted that technology use would continue with age and eventually become the norm.

Despite this, one participant queried the ability for healthcare to evolve with the introduction of new technology:

> *'… I feel like it's all, erm dry and inaccessible, it's boring and erm clunky and old fashioned, all the things that we absolutely should not be… the publication of our information is stuck in the dark ages and I feel in a world where you know me and you are able to video chat pretty easily , or erm you know we're able to access information rapidly…' (Lee, professional interview)*

As can be seen from the above quote, this could influence engagement with resources and also accessibility.

The appraisal of web-based support

This carer described differences between web-based and non-web-based resources:

> *'Erm I just think having somebody with you who is hearing you… and hearing your problem erm and being able to share with other people with not the same but similar problems erm is really really helpful… it's a different sort of support online I think… well for me anyway erm a gathering of information…which again is very helpful but to actually have personal contact, erm there's nothing like it really…' (Penny, carer interview)*

Professionals suggested the use of Skype as a solution to this barrier:

> *'…most of us do like one-to-one appointments… which is good and it's personal and everything but it's also really slow and old-fashioned, like I've got to sit in a car and drive across the city… sometimes that carer or that service user might be totally happy erm having that chat in a group on… like a Skype hangout…' (Lee, professional interview)*

The above quote highlights a further advantage of web-based support; time efficiency. The use of web-based resources could facilitate supporting a group of carers without the need to travel. For carers, this may provide the opportunity to access support that could have otherwise been unavailable. However, the majority of the sample reported a preference for non-web-based support. There was, however, uncertainty regarding whether web-based resources could provide the same level of support:

> *'…there's barely a day goes when I won't have talked to him two… three and sometimes ten or eleven times on the phone… depending what state he's in… And online support can't really take away that aspect of what you're having to do.' (Lynn, carer interview)*

> *'…I think one of the most crucial things for carers is for them to know that they're not alone, because they often feel they are completely isolated with the problem because they don't meet people in similar situations because people don't talk about it much, so erm that kind of peer support element is missing. Whether the online equivalent of, you know, talking to each other in the forum is going to, is useful or not, I don't know…' (Linda, professional interview)*

This professional appeared to be dismissive of web-based interventions, particularly their ability to provide emotional support to carers. The professional attributed this uncertainty to age, again assuming that younger carers would be more comfortable with web-based support. She displayed a reluctant acceptance of web-based resources:

> *'…so online is better than nothing and it does have the potential for interaction between carers and for vetted information to appear that's actually written from the carer's perspective and feeds into the things they want to know…' (Linda, professional interview)*

The professional also noted that some carers would prefer web-based support, but cited the importance of linking to other resources to promote individual choice. Carers supported this and noted that the intervention should refer users to other resources:

> *'…I don't know whether there's a possibility to maybe link to another websites, you know like the local authority website or the local mental health trust…website … local carers centres as well obviously, voluntary sector links…' (Heather, carer interview).*

> *'…I think it's also helpful to put you in touch with people who could, you could actually have a discussion with to help.' (Stella, carer interview)*

This was compared to a directory and could facilitate carers seeking support in a crisis, raise awareness of available resources and promote autonomy in choosing support. Professionals suggested the inclusion of information about both national and regional resources, especially non-web-based options. However, there was an awareness of the difficulty in achieving this:

> *'...a lot of the information isn't located in one place necessarily and that would, you wouldn't be able to do that either because everything changes so frequently... so it's just trying to, if you're trying to find detailed information about support and services in the area, it can be very difficult... I don't think you can replace the person on the end of the phone who has a very detailed knowledge of all local services... through networking and knowing when they change, how they change, you know finding out constantly about events, information and support groups, and things like they do, but you can't access that information online easily.' (Chloe, professional interview)*

Participants also described incorporation of web-based and non-web-based support:

> *'...you apply online to get an appointment and they come back with online exercises to keep you going until the National Health Service can actually find you a slot to go... telling you "Try this and if it doesn't work stop it immediately" kind of thing...' (Lynn, carer interview)*

However, this may be already occurring with most organisations having websites that offer advice or using the web to provide up-to-date news. One carer reported accessing web-based resources alongside completing a non-web-based course.

> *"...actually I was attending a ... course during the time I was doing this diary... so the two things tied in quite well..." (Penny, carer, interview)*

This professional noted that prior experience of web-based resources could influence perception:

> *'...this is not the fault of any quality designed intervention... but it's kind of unfortunate that there'll be, it could be tainted by association... because lots of people will have had really frustrating experiences with chatbots etc. because of the services and things like that...' (Jim, professional interview)*

As can be seen, this does not specifically relate to health interventions but focuses on general internet use. Examples could include negative comments on web-based forums. These experiences may increase a professional's reluctance to recommend support or a carer accessing web-based resources. Therefore, there could be a need to change the perception of web-based support:

> *'...in a world where maybe it's a new area to do this, erm how do you persuade people like me (laughs) that it's a good idea... to make me feel confident that I can refer people to it...' (Chloe, professional interview)*

The change in perception of web-based resources could be achieved by considering the advantages of this form of support. For instance, professionals noted the benefits of social media in raising awareness of events and resources, but cited further evidence of this:

'...I would like to think that, that things like Facebook would help carers access support and make people more aware of options and services in that area…' (Chloe, professional interview)

A further example could be the promotion of carer autonomy in accessing and searching for resources:

'…this is such a complex topic, like we're talking about an illness… which is influenced by loads of factors… it's not like a broken leg where there was a cause for the broken leg… and there's normally like one or maybe two treatment options, we're talking about a mental health problem… everyone's circumstances leading up to psychosis are different… I would say like you need to simplify it at the start just to be able to get people in, into it… if people are wanting to know about like… hypotheses that are out there about the biology of psychosis then, you know, by all means go and explore it, look read up about here's a verifiable, reliable source that talks about neurochemistry or whatever you know?' (Lee, professional interview)

However, it is also important to consider concerns regarding web-based support, such as privacy:

'…some people are well into that, you know and they've got fitbits and they'll upload all the data… I'm not so comfortable with that… the digital world has a terrible record for erm dropping the ball on erm these issues or erm privacy and… anonymity.' (Jim, professional interview)

'Security and advanced technologies are not expanding at the same speed. Security hick ups are becoming very common… Even the NHS data protection has been breached… Under these circumstances neither the patients or the carers will be willing to openly discuss their private matters.' (Brian, carer interview)

The above quotes highlight privacy concerns regarding web-based resources that may prevent use. At the time of the interview with this carer, there was prominent media attention given to the NHS data hack that may have influenced opinions regarding web-based interventions. This could indicate the impact of the media on the perception and subsequent usage of web-based resources. This could further indicate the importance of promoting trust during intervention construction.

"Bang for buck": The lack of support and resources

These participants described the limited available support for carers:

'Erm so I wasn't aware of any support at all, let alone online (laughs)…' (Rosa, carer interview)

'...I don't think there's enough online support for erm unpaid carers, especially when they're, you know, in difficult situations with people who are experiencing mental health issues…' (Ella, professional interview)

Available non-web-based support appeared to be provided by carer groups and organisations, but a lack of resources often led to a reduction in this. Some carers noted the difficulty of accessing this due to opening times and distances, suggesting that web-based support may be more appropriate.

'...even if you did want to access groups and you know carer support… face-to-face, it's they're usually when I'm at work… or they're usually miles away…' (Maria, carer interview)

Another carer had had difficulty seeking support following a house move due to differences of support provision in locations.

'...when we've changed areas, I'd found out about support groups in one area… and I found out about carers in one area but then you move to another area and you go to where you think you will get the information and they haven't actually got information about carers…' (Heather, carer interview)

Concerning web-based resources, this carer highlighted difficulty finding relevant content:

'...it's quite difficult to sort of find unless you actually specifically look, so what I found was that a lot of support was kind of hidden, it was hidden within websites…' (Maria, carer interview)

Professionals had varying views regarding available web-based information:

'...there's basic leaflets and that which the Royal College of Psychiatrists do, Mind and Rethink do but they're not, it's like 2 or 3 pages… it's not a lot of detail…' (Linda, professional interview)

'...nowadays there reams and reams, there's websites dedicated to psychosis, there's YouTube videos about psychosis, there's tons of information out there but it's not centralised, the stuff that the NHS provide is not very rich… there's not a single accessible source for it and stuff, erm or not a good one…' (Lee, professional interview)

As can be seen from these quotes, there appeared to be disagreement regarding available information. Some professionals noted that information was limited or lacked detail, while others stated that this was available but over multiple sources which could differ in quality. The difficulty finding information could again suggest a need for a centralised resource for carers.

Carers reported difficulty locating web-based information, citing that this could span across various resources. This carer noted surprise regarding information provided by the NHS:

> *'...you would have thought that the obvious place to start would be the NHS but it isn't, you know it isn't always the best place for information…' (Lynn, carer interview)*

This carer assumed that support for carers would be provided alongside support for their relative. The lack of official web-based support resulted in carers accessing web-based resources that may not have been created for carers, for instance university lectures, Citizen's Advice information or content targeted at the person with schizophrenia. These participants described web-based information:

> *'...there is an awful amount of information out there, it's very useful to have one place that focuses on this particular client group because I don't think there really is that… mental health charities tend to focus on service-users based information… to actually have carer resources in this area, I think would be incredibly valuable and pulling together things that people don't have to…' (Linda, professional interview)*

Participants further identified the lack of web-based resources specific to the carer's situation:

> *'...they have a siblings forum and that's so that's specifically for brother and sisters of anybody with mental illness or… severe mental illness, but they don't actually have a forum for other relatives…' (Ella, professional interview)*

> *'... there seems to be plenty for carers per se but erm mental health carers particularly for something like schizophrenia… erm something specific for that I think would be a very good thing…' (Penny, carer interview)*

> *'...it's things that erm are distributed by lots of different people… paranoia, delusions, hallucinations, voices… I mean there's lots of things but not everybody experiences all of them… you get an idea of the whole gamut of things that might be available and might be experienced by someone suffering from schizophrenia… but any one individual won't necessarily be exhibiting all those symptoms, or very many of them and some might occur in one instance and another might occur in another instance…' (Lynn, carer interview)*

> *'...so my opinion is that there's not much and it's not enough and it's not specific enough and I think that when you've got a relative with a serious mental illness I think there are specific needs to do with that, to do with the serious nature of the illness…' (Rosa, carer interview)*

Resources were praised if considered relevant to the carer's situation. Both carers and professionals appeared to be positive about the creation of a resource focusing on carers

of an individual with an SMI that could provide information and support. However, this professional discussed the value of specific support for carers based on their situation:

> *'...they need information about the person they are supporting which is something only a local mental health team can give them…' (Linda, professional interview)*

The provision of specific information was perceived as effecting carer health and empowerment, whilst reducing gaps in knowledge. However, although information regarding schizophrenia and symptoms was provided, there was difficulty relating this to their relative's experiences due to individual differences. Despite this, providing specific information (as described by the above quote) could raise concerns regarding the confidentiality of the person receiving care, which may subsequently reduce carer access to information. By not receiving this information, carers may not be able to provide adequate care, which could also affect their own health and that of the care recipient.

Participants noted that the web-based resource and content should be easy to locate. As previously stated, there was a concern regarding the quality of information:

> *'... conflicting information which heaven knows families have got enough on their plate without having to wade their way through that stuff as well…' (Linda, professional interview)*

The impact of the quality of information on carer health has already been noted. This also highlights the importance of easy-to-access web-based support.

This carer described her lack of awareness of web-based resources:

> *'...I have erm realised that there probably might be more information out there that I haven't be accessing...so I'm going to start looking into a few more things and see what else is out there.' (Penny, carer interview)*

This appeared to result in curiosity regarding available web-based support, in some cases resulting in participation in this project. Further instances of changes in behaviour following participation in this study included searching for more information, revisiting previous websites and signing up to a web-based course. This could indicate the need to increase awareness of web-based resources. Carers reported difficulty locating information and some appeared to place blame on healthcare professionals for not providing sufficient information. One professional from the voluntary sector noted a lack of information and advice from those working in healthcare and attributed this to an increased likelihood of searching for web-based information.

Professionals reported a concern regarding web-based resources:

> *'...I guess my fear is that if we develop all these online stuff, it'll, it'll be justification...for more cuts in a way, well like if we can do them both and not have cuts then great...' (Chloe, professional interview)*

Participants reported a lack of funding, for instance referring to the need to bid for resources and disappearing services. As can be seen from the above quote, there appeared to be a relationship between increased web-based support and a decrease in non-web-based resources. This resulted in concerns that charitable resources would liquidate. This was supported by the following carer:

> *'...our local authority had er information on services... but no money to back it up apparently...' (Eddie, carer interview)*

Participants noted the influence of location on accessing support:

> *'...it may be that one county is much, much more efficient and better and well organised and better funded or better useful mental health resources than the other...' (Lynn, carer interview)*

> *'...well to be honest it's more in, in the States compared to the UK...' (Robert, professional interview)*

One carer reported difficulty locating support for their relative as this was found outside their area and there were travel barriers. The above quote by Robert also highlights the differences in healthcare between the UK and USA. Many web-based resources are based in the USA, possibly due to the financial restraints to accessing healthcare. Carers reported accessing USA-based resources, despite acknowledging that this information may not be relevant to their situation:

> *'It's U.S based so I cannot relate to experiences of the law, services, etc.' (Rosa, carer diary, week one)*

The financial implication of web-based resources was considered by this professional:

> *'...I think there seems to be an assumption that's its going to be both more efficient...and save money, and I wouldn't guarantee that...' (Jim, professional interview)*

The professional noted the resources required for the creation and maintenance of interventions, increasing the perception of cost. The relevance of this in society was cited:

> *'...we're in a system that's, erm, very like business driven you know, everything's about cost and about efficacy and about like maximum bang for buck...it's very difficult to quantify impact...it's even more difficult to quantify for carers...' (Lee, professional interview)*

This could indicate that web-based resources may have similar financial implications to non-web-based support. The above quote raises the importance of proving the impact of

interventions in the implementation of healthcare in terms of carer and care recipient health, and financial implications.

Service involvement

Professionals emphasised the importance of service involvement with web-based resources:

> *'...I think having a reputable organisation erm but yeah umbrella-ing over it would be helpful as well. So yeah a university but also Mind or something like that would, I mean a trusted and respected mental health organisation…' (Chloe, professional interview)*

To achieve this involvement, the intervention must have demonstrated an impact on carer health:

> *'...I'm a bit reluctant to offer that until I've seen evidence that it worked because I feel some degree of responsibility like around offering things to people in crisis…' (Chloe, professional interview)*

The intervention should also provide detailed information and the ability for further discussions. Failure to achieve these points could influence professionals directing carers to the web-based intervention. Professionals identified assistance services could provide for carers:

> *'...we could do like erm a mini sort of training things where we could go actually, you know, to get the online erm intervention up and do like a little training session... for people who are a little bit wary or not sure, we would really try and encourage them and show them how to use the site and er you know, obviously promote the benefits of having access to erm the online intervention as well.' (Ella, professional interview)*

Professionals could influence the appraisal of web-based resources by increasing trust and showing the benefits. As the above quote illustrates, organisations can provide training sessions to increase technological literacy and encourage utilisation. Whilst this may indicate the importance of human interaction and assistance, it could also suggest that ensuring service involvement with web-based interventions overcomes concerns regarding loss of funding and risk of closure.

Professionals reported that if an intervention was to be routinely offered as support, this would need to be secure, be risk assessed and ensure confidentiality of users. This appeared to relate to professional responsibility towards promoting carer health and consideration of the vulnerable nature of carers.

One professional noted the development of reputation:

> *'...if it was something that was quite, started to build, get quite well know... that people can say "Oh I know, I'll go onto that site and I can get support from there"...' (Ella, professional interview)*

This could indicate that involvement with services may be a step towards developing the reputation of the intervention.

Summary

Figure 4.6 outlines the relationship between the above four subthemes. The evolution of technology considered the transformation towards digital-based support in healthcare. This was credited with the reduction in non-web-based resources and therefore was associated with a negative appraisal of web-based interventions. By collaborating with services to develop, construct and maintain web-based resources, this could influence professionals' appraisals of these interventions. Services were interested in being involved in facilitating web-based intervention usage, for instance assisting individuals in using technology.

4.4.6 Further consideration founded on qualitative data

Aligning from the research underpinning this thesis, this section will provide a more in-depth examination of the relationship between carer and care recipient health as identified in the theme expertise via experience. This is further considered with previous research and is presented in figure 4.7.

The below figure proposes that carers and individuals with schizophrenia (as with the general population) have a level of mental health represented as a continuum between wellness, indicating ideal mental health, and unwellness, referring to mental illness and distress. It is expected that wellbeing would naturally fluctuate in accordance to life changes and, in some cases, interventions would not be required. For instance, distress following a bereavement would be considered natural as this is likely to be interim. However, if distress is enduring, therapeutic support may be required. Therefore, carer mood will naturally fluctuate throughout everyday life and situations relating to the caring role. Similarly, enduring distress could result in referral to therapeutic support to improve carer health. The findings of the research informing this thesis have demonstrated a relationship between carer and care recipient health, in line with previous research

(Kuipers, 2006; Jansen et al., 2015; Susatani et al., 2018). For instance, carers described distress experienced with their relative's FEP and subsequent diagnosis. Similarly, interviews highlighted the impact of the carer's health on the care recipient.

It is important to acknowledge the influence of appraisal of mental illness and carer responsibility on health and support seeking in alignment within the stress, appraisal, coping model (Lazarus and Folkman, 1984). For instance, a negative appraisal regarding the risk of violence with mental illness can result in fear, increasing 'moral panic' and stigma (Scott, 1998). In contrast, promoting hope in carers could improve carer health and, as a result, increase care recipient health.

During FEP, an individual will be prescribed antipsychotic medication or referred to CBT or family intervention (NICE, 2014). For carers, FEP can also indicate a caring role and entitle them to support, for example a carer assessment. However, key barriers to accessing support include failure to identify any negative effects of the caring role on their health or prioritising their relative's health.

The relationship between carer and care recipient health could indicate the effectiveness of a joint intervention targeting carer and care recipient health. Previous web-based interventions have prioritised carer health and have not assessed the potential impact on the care recipient (Glynn et al., 2010; Lobban et al., 2017; Gleeson et al., 2017a). Only one web-based intervention assessed impact on carer and care recipient health, with both parties having access to the resource (Rotondi et al., 2010). Findings indicated increased knowledge of schizophrenia, however it had little impact on health.

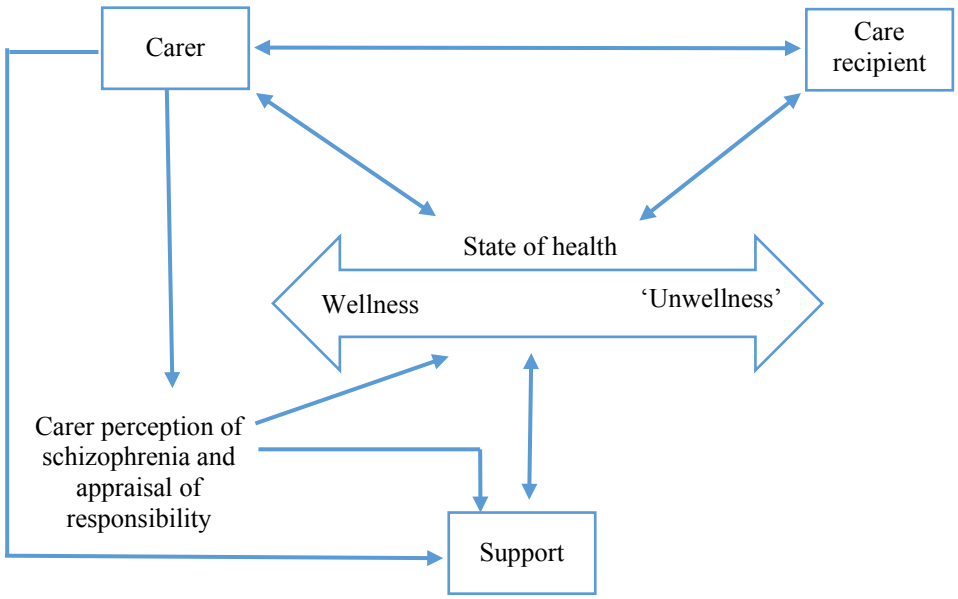

Figure 4.7 A figure depicting the relationship between carer and care recipient health.

4.4.7 Assembling the analysis across themes

The five themes and associated subthemes identified from the thematic analysis of interviews have been presented, defined and illustrated. This section will now summarise these themes and outline key differences. See figure 4.8 for a visual depiction of the relationship between themes. This figure classifies empowerment through knowledge as a central point due to the prevalence across themes. This is similar to a grounded theory approach that aims to identify a core category that interlinks with others (Corbin and Strauss, 2008). Despite this similarity, the research informing this thesis is underpinned by a critical realist approach as illustrated in the conceptual framework presented in chapter three. This aspect is included to highlight the relationships between themes, indicating the complexity of the focus of interest, and to facilitate reader understanding of the assembled analysis.

The first theme focuses on carer development of expertise based from experiences of the caring role. Carers reported a need for information concerning management of situations encountered, stating that current web-based information would have been beneficial when beginning this role. Some carers indicated that providing this information could assist newer carers and prevent the associated distress with learning via experience. There appeared to be blame placed on healthcare professionals for failing to provide information, resulting in carers undertaking a self-directed search for information. One participant reported the power imbalance between carers and professionals, arguing for complete disclosure of information. Whilst the internet could provide increased access to professionals, such as email exchange, the differences between carers' and professionals' views of responsibility could create difficulty in understanding the other party's position. Carers focus on the care recipient's needs over their own health, which can also indicate a key barrier with engaging with a web-based resource.

Similarly, the second theme detailed carer empowerment through knowledge acquisition. Acquiring information was perceived as increasing carer empowerment, especially if content included a range of perspectives that could enable carer autonomy. Information relating to situations and expectations of the caring role could minimise distress and assist management of the caring role. Further evidence of empowerment included carers utilising web-based information to influence treatment or aid discussions with healthcare professionals. However, despite this, carers appeared to view professionals as the

expected information providers, suggesting that this provided reassurance that this information was of high quality.

This theme outlined a needs-based approach to web-based information seeking and, in doing so, it suggested the importance of meeting carer individual needs to facilitate engagement and possible subsequent impact on health. However, this also noted the balance between a needs-based approach to information seeking and difficulty accessing this due to emotional distress. While web-based information could relate to factual content concerning the illness, it could also refer to personal blogs providing understanding regarding the individual's experience. Finally, participants debated the availability of web-based information, with some reporting difficulty finding this due to the lack of a centralised resource.

Participants highlighted the importance of connection and understanding, which was often received via support groups. Involvement in web-based forums provided carers with the ability to share advice and resources from previous experiences, seek answers to questions, or observe conversations without needing to interact. One example consisted of advice regarding communicating with an ill relative. Participants debated whether web-based forums could provide a human factor, especially in times of distress; the lack of which could influence appraisal of this resource. Regardless, this indicates that web-based forums could provide a person-centred form of support whilst also encouraging carer empowerment. Despite this, carers reported limited availability of web-based forums, resulting in one carer creating a group via social media. Another carer noted that a regularly used forum was no longer available, and interestingly some professionals remained unaware of this. One professional suggested that organisations were concerned regarding the lack of control over content with web-based information and the associated risks of over disclosure. The risk of sharing incorrect or harmful information could impact on carer and care recipient health. These concerns could influence appraisal of web-based resources and referral to these resources.

Personal preference: Considering the accessibility of the internet interacts with two themes; Empowerment through knowledge and Expertise via experience. Participants raised concerns that information surplus could impact carer engagement and adherence to a web-based resource. Professionals reported referring carers to resources based on interpretation of their needs and proficiencies. Further needs could relate to disabilities that could influence engagement with web-based information. One participant suggested that a web-based algorithm could provide a personalised approach to identifying carer

informational needs. Relating to expertise via experience, participants argued the importance of providing information in lay terminology, as opposed to from a medicalised perspective, to facilitate understanding. Expertise could also relate to technological knowledge; participants suggested that users may struggle to utilise web-based resources without prior skills obtained in employment or in an educational setting.

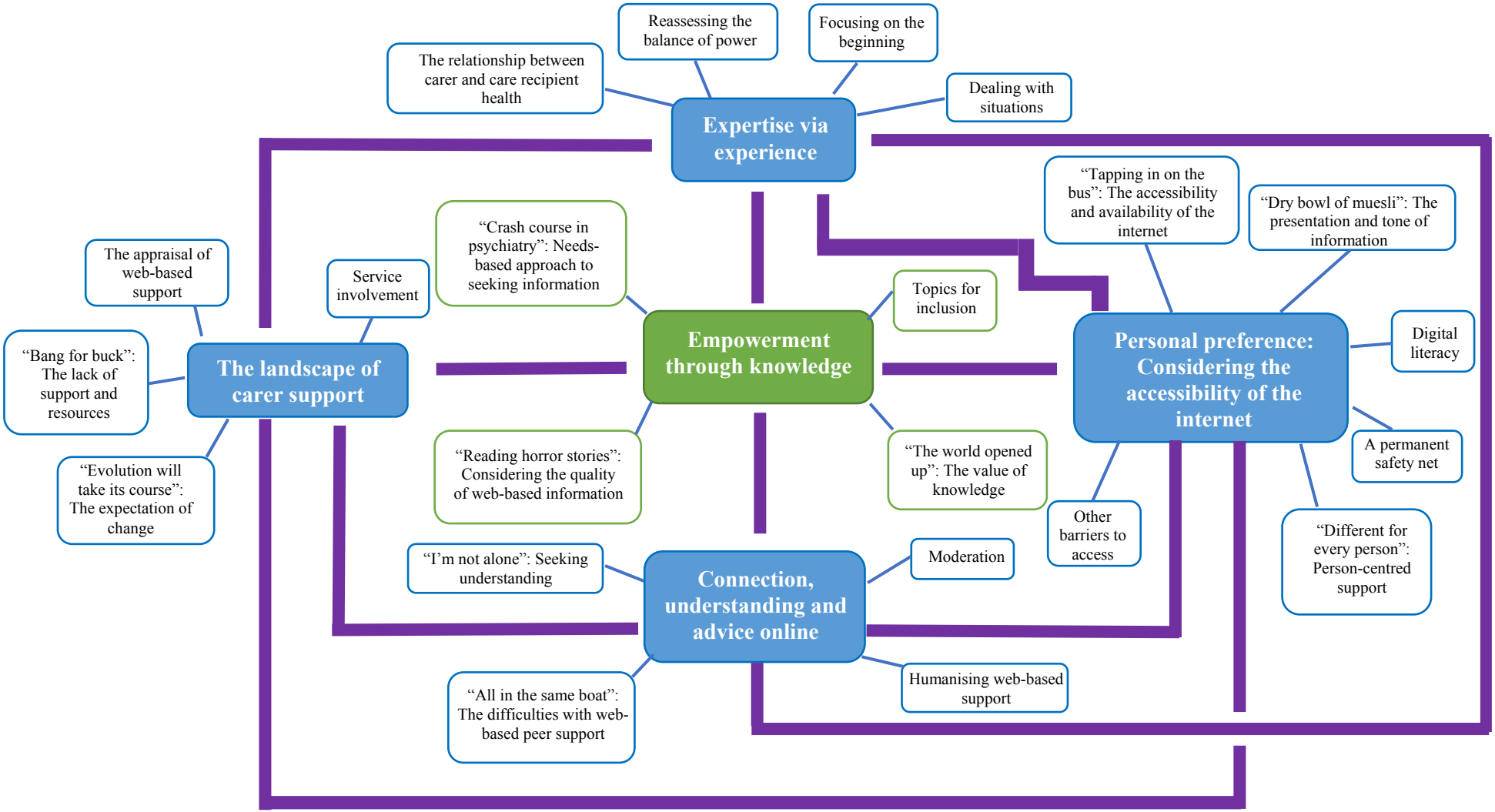

Figure 4.8. The thematic map detailing the five themes and associated subthemes.

Finally, landscape of carer support provided an overview regarding carer support and the appraisal of web-based resources. Participants debated the accessibility of web-based information for carers with some citing that this was limited. Others noted that specific information was not available, indicating the importance of a person-centred approach. In order to be trusted by professionals and their subsequent referral to carers, web-based information would need to provide detailed high-quality information. A further factor in increasing perceived trustworthiness of an intervention could include overshadowing by a reputable organisation indicating the involvement of expertise.

Figure 4.8 displays the relationship between the themes identified from the individual interviews. The relationship between individual subthemes within a theme has already been acknowledged in presentation of the qualitative findings underpinning this thesis. The following section will unpack two key elements from the above analysis; appraisal of web-based resources and expertise via experience.

Whilst there was evidence that participants could view web-based resources as advantageous, for instance in terms of privacy and increased autonomy, the majority of the sample indicated a negative appraisal of web-based resources. Identified factors are as follows;

- Inferiority of web-based information.
- Web-based forums and the risk of incorrect advice or over disclosure.
- Lack of humanisation.
- Concerns regarding superseding non-web-based resources.
- Level of connectedness compared to quality relationships.

Consequently, carers were dismissive concerning the usefulness of web-based resources and did not recognise online information as a form of support. This could indicate difficulty engaging with or utilising a web-based intervention. Regarding professionals, this could designate averseness towards referring carers to web-based resources.

Despite this, web-based information enabled the advancement of carer empowerment, for example through the self-directed search for information relating to the illness and caring role. Carers discussed the effect of web-based information on their relative's health and the caring situation, for instance in changing medication. A supplementary example is sharing advice and experiences through web-based forums. However, professionals highlighted several concerns regarding the quality of web-based information and advice shared through forums. The latter resulted in suggestions of a professional-moderated

forum. Whilst moderation can have clear benefits in terms of risk, it is important to consider the implications of this on carer empowerment and healthcare collaboration. This could continue to place professionals at a more authoritative position within the healthcare model. Conversely, carers reported viewing professionals as providers of information, which contradicts the present collaborative healthcare model.

Having unpacked two key elements from the thematic analysis, the following figure will expand on the initial relationships between themes by presenting further connections at the sub-theme level. This will highlight the complexity in accordance to complexity theory informing this thesis (see figure 4.9).

The above diagram expands on the complexity of interactions between subthemes, for instance the link between the subtheme 'Crash course in psychiatry: Needs-based approach to seeking information' and 'Evolution will take its course'. Participants reported requiring information to assist them in managing the caring role and in promoting empowerment. The search for information was actioned by the identification of a need, often surrounding a situation encountered within the caring role or via diagnosis. However, carers reflected on the evolution of existing support (including web-based information) following initial searching following diagnosis. Carers also stated the expectation of the continued dominance of web-based support following the aging of digital natives.

Further examples include the connection between the subthemes 'I'm not alone: Seeking understanding' and 'The world opened up: The value of knowledge'. This relationship consists of information sharing within carer web-based forums and the result of receiving this. For instance, one carer reported positive outcomes following receipt of recommendations and information. Finally, carers reported the value of assistance in overcoming situations in the caring role, therefore attributing this as a topic for inclusion on a web-based intervention.

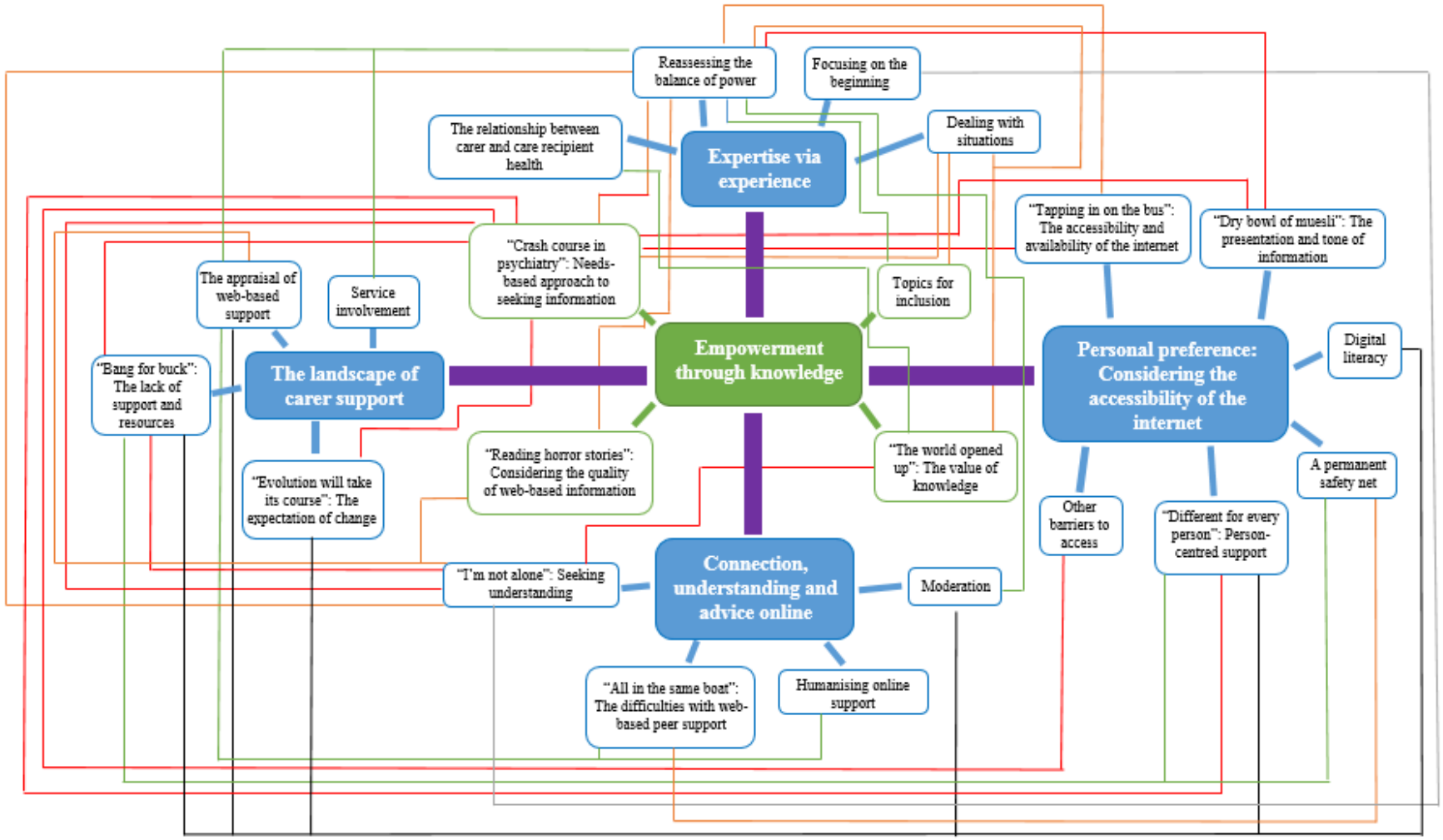

Figure 4.9. Thematic map detailing connections between subthemes

4.4.8 Summary

This section has presented the qualitative findings of the research informing this thesis established from the individual interviews with carers and professionals. Five themes were defined, outlined and illustrated with quotes from interviews. Initial discussion regarding themes was included within this section and will be considered in more depth within the following chapters.

The interaction between themes and subthemes was delineated and discussed in relation to carer adherence to a web-based intervention and its potential impact on health. The following section will present the generative mechanisms and contexts deriving from the individual interviews.

4.5 Summary of research findings

The descriptive and summative results from the quantitative data has suggested an increase in wellbeing and QoL following the use of web-based resources over a 6-week period. However, these findings suggested an increase in depressive symptoms. QCA provided a greater insight into the causal conditions influencing a positive and negative change in wellbeing scores. This insight was further enhanced with the findings from the thematic analysis that highlighted the value of knowledge and identified key barriers relating to accessibility. Participants reported the value of web-based resources and the assumed impact on wellbeing. However some did note that this was likely due to the receipt of support as opposed to the web-based method.

The QCA analysis complements findings from the thematic analysis. The summary of the QCA tentatively suggested that the association with increased emotional distress and a higher rate of web-based resource access could be related to carer supportive needs within the caring role. The findings from the thematic analysis has highlighted the importance of a needs-based approach (including emotional needs) to information seeking. This could suggest that carers encountered a stressful situation, which resulted in a negative response and subsequent use of web-based resources to overcome this issue. This is further supported with the identification of a higher rate of web-based resource access being associated with an increase in ability to care (see 4.3.1 Weekly web-based support access).

The second QCA analysis could support the value of considering individual needs and creating a person-centred support, as raised within the thematic analysis. For instance, this QCA suggested the influence of familial relationships and employment status on the resulting outcome measures. Consideration of these contexts and additional factors as determined through individual interviews can facilitate the access and adherence to web-based resources.

4.6 Mechanisms and key factors identified within analysis

As outlined in chapter three, a critical realist perspective aims to identify the generative mechanisms associated with the phenomenon of interest. Whilst a brief overview relating to the influence of generative mechanisms and context on intervention outcomes has already been included, this section will further explore this concept.

Blom and Morén (2015) described three levels of mechanisms; micro, meso and macro. The micro level relates to "powers in terms of causes, motives, considerations, choices and social interaction at an individual level" (p64). For example, oral and written text, and role expectations according to gender. Meso mechanisms refer to choices and motivations at "a group or organisational level" such as interactions at a group level and social structures. Finally, the macro level consists of actions at a societal level relating to interaction between societies and material structures (such as the governing political party).

Supplementing complexity theory, Pawson (2008) states that mechanisms are potential causal factors constituting towards an outcome. This suggests that multiple mechanisms are possible, however they are reliant on the individual activating these via choice and the correct context for this to occur (Pawson and Tilley, 1997). Therefore, mechanisms may not be activated and, as a result, fail to provide an effect. This could indicate that beneficial effects of a healthcare intervention could fail to occur due to implementation in an incorrect context. It is possible that the beneficial effects could have been achieved via different contexts. Thus, it is important to consider the contexts that facilitate or debilitate generative mechanisms, which Pawson and Tilley refer to as context-mechanism-outcome, otherwise known as CMO, propositions. Regarding context, Pawson (2008) suggested that these are made up of four layers; individual, interpersonal, institution and infrastructure. For example, the success of a health intervention on patient

outcomes could depend on the following; patient motivation and adherence, family member support and relationships, healthcare context and staffing, wider social and societal views and provision of health interventions.

Blom and Morén (2015) proposed a five-stage analytic framework to identify generative mechanisms. See Table 4.9 for a description of the framework and implementation in this project.

Table 4.9. The analytical framework undertaken to identify generative mechanisms and contexts.

Framework	Description
Observation/ description	The use of a weekly diary highlighted web-based support use by carers of individuals with schizophrenia. Individual interviews with carers and professionals have further provided a description regarding web-based support use and its implication on carer wellbeing and QoL. These interviews have also highlighted barriers relating to web-based support use by carers.
Division and sorting	This stage refers to the coding and sorting of information into categories. Thematic analysis, as proposed by Braun and Clark (2006), provided a systematic and flexible framework towards the coding and identification of themes. The findings of this analysis have been presented in this chapter.
Abduction	Abduction refers to the interpretation of events as indicative of another abstract phenomenon. The QCA has presented causal conditions associated with positive and negative changes in carer emotional health. Following initial proposals within the individual interviews, the relationship between carer and care recipient health has further been considered in more depth. Chapter five presents the proposed framework for the construction and evaluation of a needs-aligned web-based intervention aiming to improve carer and care recipient wellbeing and QoL. Future research could continue to assess the impact of these events on carer emotional health.
Retroduction	This stage relates to the formulation and testing of mechanisms, in particular what contexts are required for the activation of the generative mechanisms. This section provides proposed tentative contexts associated with the triggering of generative mechanisms. Future research can further assess the implications of these contexts on generative mechanisms.
Contextualisation	The final stage of the framework refers to studying the contexts of situations which trigger generative mechanisms and how these mechanisms are expressed.

The identified contexts and generative mechanisms deriving from the individual interviews, comments from weekly diaries and QCA are presented in Table 4.10. The levels of mechanisms and layers of contexts as defined by Pawson (2008) and Blom and Morén (2015) are also provided.

Table 4.10 The generative mechanisms relating to web-based support use identified from the studied data.

	Classification	Type	Location	Key issues
Degree of accessibility and availability	Context	Individual	Interviews	**Carer age and practicality of web-based resources**: Age could be a factor regarding web-based support use. Participants suggested that older carers may struggle to use and accept the offer of web-based resources. They indicated that younger users would be more confident and more likely to use the internet as a form of support.
	Context Mechanism	Institution Meso	Interviews	**Centralisation**: Centralisation relates to the location of support; local or national. This would also be relevant if a web-based intervention includes a referral feature. Regarding web-based resources, participants reported that information was often spread across several sources, resulting in frustration when seeking to identify relevant content. Thus, the creation of a single resource containing relevant support could improve usage and reduce frustration.
	Mechanism	Individual	Interviews QCA	**Carer level of understanding and technological literacy**: Technological literacy and confidence using this medium could be a barrier to accessing web-based resources. This mechanism could be related to carer age and previous employment or educational experience.
	Context	Individual; institution; infrastructure	Interviews	**Accessibility and affordability:** This mechanism refers to carers' ability to afford technological devices and the accessibility of these via multiple platforms.
Degree of intended impact upon carer and care recipient health	Mechanism	Individual	Interviews QCA	**Clarity and intention**: This mechanism highlights the relationship between carer and care recipient health with the suggestion that by improving one, this will improve the other. This could indicate an indirect effect on care recipient health following carer participation in a web-based resource. For instance, information leading to the change in treatment or the care recipient's engagement in an activity. This could further suggest that carer access to the

Table 4.10 continued:

				web-based resource may be dependent on care recipient health and situations encountered within the caring role.
	Mechanism	Individual	Interviews	**Limitations**: The acquiring of negative or misleading web-based content could indicate an increase in carer distress which may impact on the care recipient.
Degree of quality of web-based support	Mechanism	Meso	Interviews	This mechanism refers to **carer and professional perspectives regarding the quality and usefulness of information**. To facilitate intervention usage and impact carer health, information should be relevant to the carer's situation and needs. To be considered a high-quality resource, information should be evidence-based and provided by healthcare professionals with input and content by carers.
	Mechanism Context	Micro Individual; Institution	Interviews	**Target audience**: This refers to whether the web-based resources meet different carer supportive needs and, in this sense, relates to context and mechanism. For instance, potential carers who may be seeking information regarding diagnosis, new carers who are beginning a caring role and long-term carers who have completed a caring role over a number of years.
	Mechanism	Micro	Interviews	**User involvement**: This mechanism indicates the usefulness and concerns regarding advice through peer support groups. This can also refer to the carer involvement in the development and maintenance of web-based resources and content.
Degree of specificity of web-based support	Context	Interpersonal	Interview QCA	**Care recipient condition:** This mechanism can relate to individual conditions or experienced circumstances and symptoms. This could require input from healthcare professionals regarding what information would be beneficial to family members.

Table 4.10 continued:

	Context Mechanism	Individual Micro	Interviews	**Carer and care recipient needs:** refers to the ability for a web-based resource to fulfil carers' needs regarding information and support. This could also refer to needs relating to the care recipient, for example searching for events or activities to reduce isolation.
Degree of interactivity of web-based support	Mechanism	Micro	Interviews	**Active or passive engagement:** individual interviews highlighted the individual differences between participants. For instance, demonstrating an active interaction with web-based forums by posting questions or responding to previous posts. Alternatively, one carer noted a passive interaction, citing a preference of viewing posts as opposed to directly commenting.
	Mechanism	Meso		**Information sharing and knowledge:** denotes the presentation of information on a web-based resource. For instance, written information, video or audio recordings, and live events or discussions via forums.
Degree of empowerment and control	Mechanism	Meso	Interviews	**Information sharing:** This mechanism refers to the importance of providing information to carers of an individual with schizophrenia or psychosis. This mechanism could refer to written information, visual or audio, and content obtained through web-based forums. Participants suggested that information could increase empowerment over the caring situation and, as a result, this could impact on carer health.
	Mechanism	Micro	Interviews	**Carer responsibility and expectations:** illustrates the importance of encouraging carers to acknowledge their own supportive needs and their onus towards their relative's health. This mechanism could also refer to professionals' responsibilities and roles in promoting health; as carers suggested that knowledge of this could impact relationships. Finally, expectations relates to newer carers and refers to events and emotions encountered within the caring role.

Table 4.10 continued:

	Mechanism Context	Institution Meso		**Permanence:** This relates to providing access to resources that carers perceive to be useful without risk of loss. Within the individual interviews, carers discussed that web-based resources may no longer be available, despite their noted usefulness.
Degree of 'humanisation' of web-based support	Context Mechanism	Individual Micro	Interviews	**Needs-based and person-centred:** Individual interviews have identified a needs-based approach to seeking web-based resources. This could relate to situations encountered during the caring role or the carer's emotional needs. To promote adherence and engagement, a web-based resource must be able to meet carers' supportive needs whilst also meeting their requirements for support provision.
	Mechanism	Micro		**Reducing technological remoteness:** This mechanism refers to the attempt to reduce technological remoteness and complement non-web-based resources. Examples could be including videos and live discussions that feature individuals.
Security	Mechanism	Meso	Interviews	**Perspectives of safety by participants:** Professionals advocated the importance of security and carer ability to use this safely without risk. Perspectives of safety and security could influence carer usage and professional recommendations, and referral to the web-based resource.
Appraisal of web-based resources	Context	Individual	Interviews	Individual interviews have highlighted a **negative appraisal of web-based resources** resulting from previous experiences, age, remoteness of the medium and the perception that this impacts non-web-based resources. This mechanism could influence professional and carer perception of and engagement with web-based resources.

Dawkin et al. (2015) outlined the difficulty of identifying mechanisms and contexts. These authors further proposed an extension of CMO configurations (as proposed by Pawson and Tilley, 1997) and identified a further categorisation of mechanisms; resource- and reasoning-specific. Resource mechanisms relate to generative mechanisms originating from the health-based intervention. Reasoning mechanisms focus on the properties regarding the individual, such as anxiety. In this sense, the impact of an intervention is dependent on included resources (resource mechanisms) occurring within specific contexts. This influences the behaviour of participants (reasoning mechanisms) which, in turn, results in an outcome.

The proposed generative mechanisms (see table 4.10) originating from the research informing this thesis are presented in Figure 4.10. This figure is adapted from that provided by Dawkin et al. (2015). The generative mechanisms and contexts identified in this chapter were used in the development of a framework for the construction and evaluation of a web-based intervention.

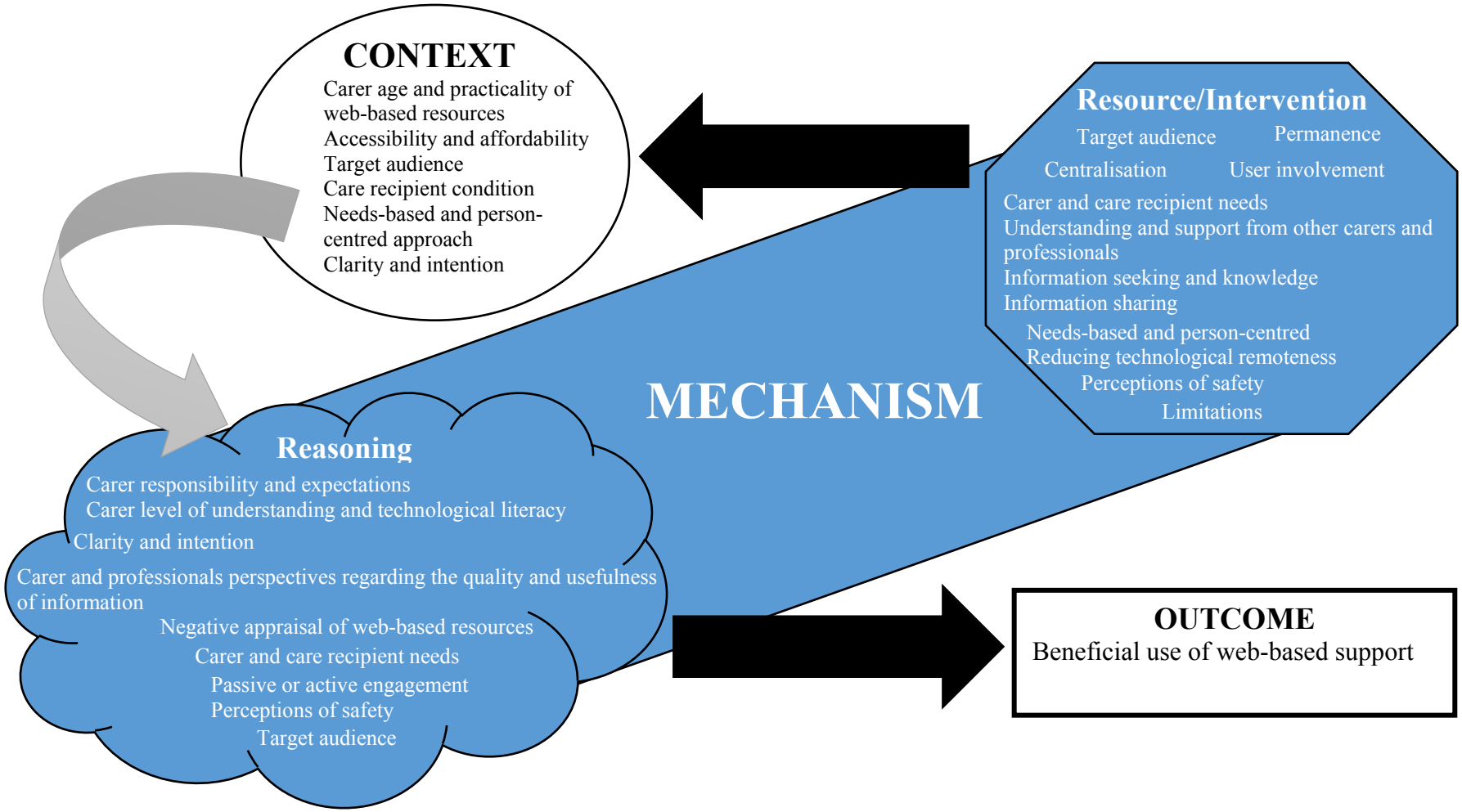

Figure 4.10. The presentation of mechanisms categorised into reasoning and resource/intervention (Figure adapted from Dawkin et al., 2015).

4.7 Chapter Summary

This chapter has presented the findings originating from the research informing this thesis. This began by reporting quantitative findings regarding the access of web-based resources over the 6-week period. Following this, findings from the health questionnaires were presented to identify the impact of web-based resources on carer health.

The first QCA suggested key causal factors relating to demographic aspects, including prior web-based support use, and the impact on health outcomes. Second, an additional QCA suggested causal conditions influencing the use of web-based resources during the 6-week period, using week 3 as a key point of access. The prime implicants from each analysis will be discussed in relation to the other findings and with previous literature in Chapter six.

This chapter presented findings from qualitative interviews consisting of 5 themes; 'Empowerment through knowledge', 'Connection, understanding and advice online', 'Personal preference: Considering the accessibility of the internet', 'The landscape of carer support', and 'Expertise via experience'. An assemble analysis and identification of the relationships across the five themes was also provided.

Finally, this chapter concluded by presenting the generative mechanisms and contexts identified from analysis of individual interviews. The typologies of mechanisms and contexts were also outlined. The following chapter will present a framework for a web-based intervention for carers of individuals with schizophrenia or psychosis.

Chapter 5. Further discussion: Developing a needs-aligned framework for the construction and provision of web-based carer support

5.1 Chapter overview

The purpose of this chapter is to present and discuss a carer needs-aligned framework (CNAF) for the construction and evaluation of a web-based intervention for carers of individuals with schizophrenia or psychosis. Aligned with the research findings informing this thesis, the purpose of this framework is to increase carer wellbeing and QoL by maximising empowerment and perceptions of control over the caring role. This chapter will begin by reporting the key elements to develop a framework for the construction and evaluation of need-aligned web-based interventions identified from the qualitative interviews with carers and professionals, before turning to illustrative examples of this process from three of the carer sample. Key considerations for resource developers are discussed in relation to previous literature.

Attention turns to the presentation of proposed components of a web-based intervention for carers of an individual with schizophrenia or psychosis. The proposed components of the web-based intervention are outlined and considered in relation to previous research. This chapter will consider further tentative considerations towards the identified need-aligned framework and will present and briefly summarise the inclusion of additional proposed intervention components.

5.2 Key elements of a carer needs-aligned framework

The key elements of the CNAF are presented below in Figure 5.1. The CNAF was derived from the identification of generative mechanisms and contexts attributed to the benefits of web-based resources (presented in chapter four). These generative mechanisms and contexts originated from the thematic analysis and QCA, which further informed the

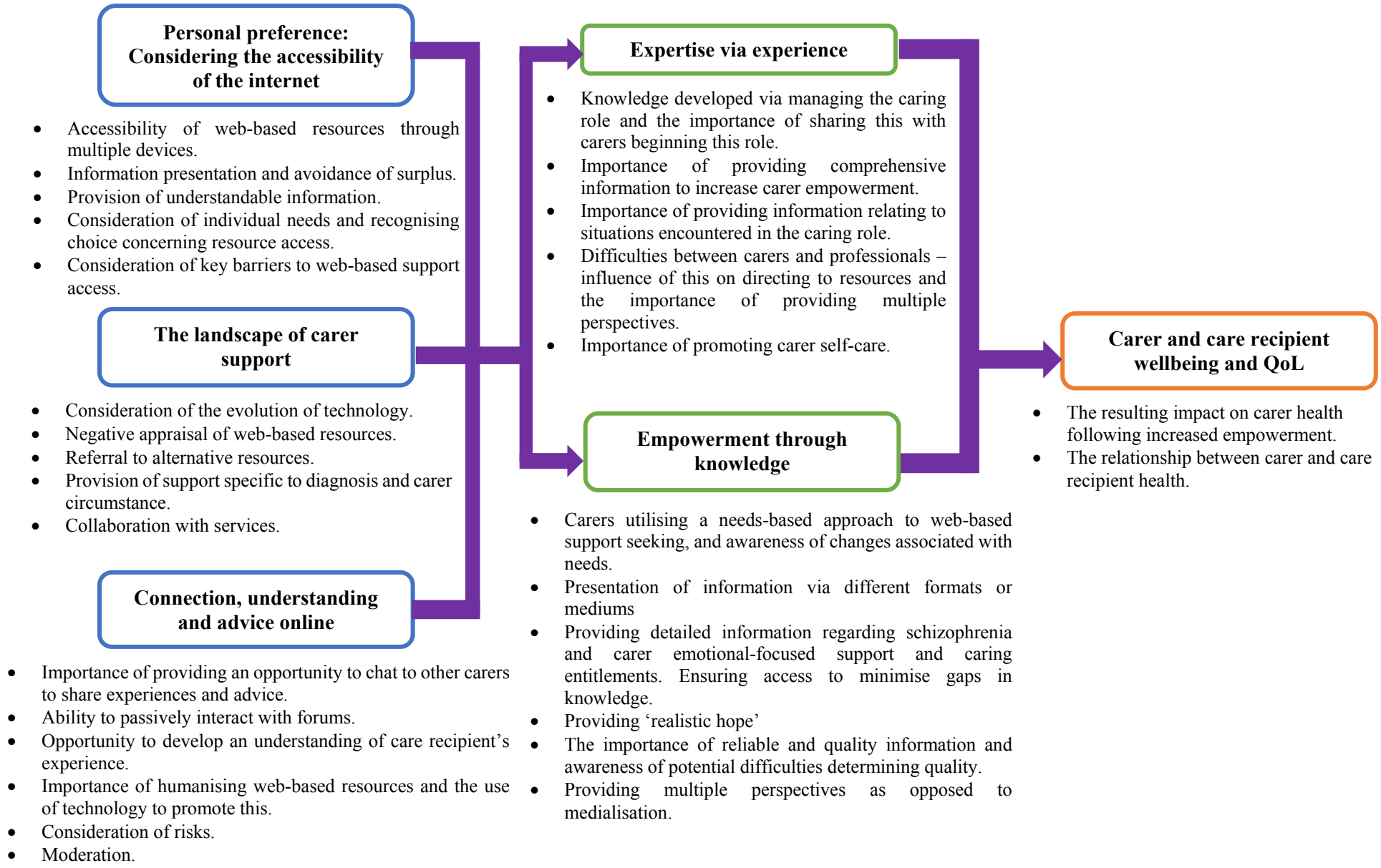

Figure 5.1. Key elements aligned with the CNAF for a web-based intervention

CNAF. The figure consists of five elements relating to the themes identified via the findings of the research informing this thesis. These five factors contribute to the aim of the web-based resource; to improve carer and care recipient wellbeing and QoL.

5.2.1 Carer illustrative examples

This section will outline the key elements of the above needs-aligned framework and draw on three illustrative examples from the carer sample to facilitate reader understanding. The three participants were selected due to variation in personal circumstances and web-based support use to highlight individual differences in the access of support. Further demographic information on these participants are provided below. Subsequently, the key elements are discussed in relation to previous research and literature regarding carers of individuals with schizophrenia or psychosis.

5.2.1.1 Vignette 1: Rosa

Rosa is 57 years old and cares for her 35-year-old son diagnosed with schizophrenia. She has held a caring role between 10-20 years and currently lives separately from her son. Rosa provides care for her son between 5-10 hours a week and reported receiving no support at baseline. She reported using the internet for support and over the 6-week period accessed web-based forums, videos and information.

5.2.1.2 Vignette 2: Eddie

Eddie is a retired 69-year-old male who has been caring for his 35-year-old son who was diagnosed with schizophrenia. He has held a caring role for 10-20 years and provides care for his son for 10-15 hours per week. Eddie reported living separately from his son. At baseline, Eddie reported no support for his caring role but stated he was an internet user, noting that he set up a web-based forum for carers. During the 6-week diary, Eddie reported accessing web-based information.

5.2.1.3 Vignette 3: Lynn

Lynn has been caring for her 37-year-old son who was diagnosed with schizophrenia. She is 71 years old and is retired. Lynn has held a caring role between 10-20 years and does not live with her son. She cares for her son between 5-10 hours a week and reported receiving support for her role at baseline. She did not use the internet to access support at baseline, however she did report searching for web-based information and email communication.

5.2.2 Overview of the carer needs aligned framework

As can be seen from Figure 5.1, there are three fundamental prerequisites towards carer and care recipient wellbeing and QoL;

- Personal preference: Considering the accessibility of the internet.
- The landscape of carer support.
- Connection, understanding and advice online.

Personal preference: Discussion of the accessibility of the internet refers to the availability of web-based resources via multiple devices at any time. In some instances, web-based resources were considered a permanent safety net that could be accessed when required. However, participants identified the importance of information presentation and tone, with excessive and medicalised content precluding engagement. This element incorporates the carer's choice and autonomy in accessing web-based support or non-web-based alternative resources. Finally, this considers barriers to technological access such as digital literacy, financial concerns and the influence of the care recipient. The consideration of barriers to access can be valuable in the construction and evaluation of a web-based intervention. In alignment with critical realism and complexity theory, this can identify generative mechanisms required to cause or inhibit an outcome.

Regarding the three carers identified as illustrative examples, Eddie reported difficulty accessing some forms of carer support within the weekly diary. He attributed this barrier to his son, who prohibited access due to concerns of anonymity. Although not directly stated, this concern could be due to concerns regarding stigma or representative of schizophrenia symptomology. Neither Lynn or Rosa experienced this barrier, however the latter conveyed the difficulty she experienced attempting to access a web-based forum despite having proficient technological skills. This indicates the importance of an easily-

accessible intervention and the provision of support to enable access regardless of technological literacy. Of the three carers, Rosa and Eddie chose to actively engage with web-based forums. In contrast, Lynn reported a passive engagement with forums, identifying the possible benefit of viewing posts but appearing reluctant to actively interact with this medium.

The landscape of carer support denotes the evolution of technology, for instance the transition from computers to smartphones and, therefore, increasing access to the internet. However, all participants demonstrated a negative appraisal towards web-based resources and reported a preference for non-web-based support. As a result, participants highlighted the importance of referral to alternative non-web-based resources. The negative appraisal of web-based resources indicate the need for initial engagement or meeting to discuss the advantages of technological support and minimise any concerns. This initial assessment could be achieved in collaboration with voluntary services. This element further considered key barriers to the access and provision of web-based support, such as financial restraints and concerns regarding privacy.

Eddie recognised the evolution of technology by observing the increased amount of information available for carers that was previously unknown. The three carers chosen for illustration purposes appeared to easily access and engage with web-based resources and indicated regular use. However, carers identified difficulty accessing non-web-based support for themselves and their relative; for instance, Eddie described being unable to refer his son to therapeutic support due to living outside of the catchment area. The three individuals described limited support for carers of an individual with schizophrenia or psychosis, and consequently Eddie created a web-based forum to fill this deficit. Rosa further indicated the value of support regardless of format, however acknowledged benefits of web-based forums such as discretion and the receipt of understanding and acceptance. Lynn appeared to be inquisitive regarding web-based resources with the assumption she was not accessing all resources or not using this to the full effect. In this sense, a referral feature directing users to alternative forms of web-based and non-web-based resources could be valuable to carers.

Finally, Connection, understanding and advice online raises the importance of conversing between carers to distribute experiences and advice. Web-based resources can allow carers the ability to receive understanding from others with similar experiences. This can facilitate active and passive interaction with web-based resources, thus promoting carer choice regarding usage. Posts by an individual experiencing schizophrenia can increase

carer understanding regarding the illness and experiences. However, in some instances these posts can be distressing to carers. Further risks can include sharing incorrect advice or over disclosure of sensitive information, thus indicating the importance of moderation in minimising risk. Participants raised the importance of humanising web-based resources to reduce remoteness, examples of which include live streaming and videos. Humanising a web-based forum could increase adherence and engagement with an intervention and, therefore, impact carer health.

In reference to the illustrative examples, as previously identified, Rosa and Eddie are regular users of web-based forums. Rosa was positive regarding web-based forum use and described the benefits of communicating with individuals with psychosis, reduced isolation and knowledge exchange. Rosa appeared to perceive web-based resources as personal support for her own needs, and also noted that remoteness could be useful when distressed. During his individual interview, Eddie stated the creation and subsequent moderation of a web-based forum. However, Eddie did not report use of this within the weekly diary. Eddie was negative concerning the use of forums by individuals with schizophrenia when unwell, perceiving these as disruptive as opposed to beneficial for understanding. As previously noted, Lynn was ambivalent regarding the value of web-based forums and therefore did not actively engage with this form of support. However, she did refer to being a member of a local carer group.

As highlighted above, these three fundamental aspects feed into two further elements;

- Expertise via experience
- Empowerment through knowledge

Expertise via experience suggests that knowledge is developed through management of the caring role. Acquiring information could increase carer empowerment and perceptions of control over the caring situation. However, participants noted that the source of information and support may influence adherence to the resource. For instance, continued difficulties between carers and professionals could reduce the likeliness of adherence to content. The relationship between carer and care recipient health could indicate the importance of promoting carer self-care, which participants reported as likely to be disregarded.

All three carers reported seeking information relating to situations encountered within the caring role; in particular responding to or improving communication with the care recipient. For example, Eddie reported searching for assistance on correctly responding

to his son with the assumption that this could be improved. Eddie reported limited support and direction from healthcare professionals, indicating a self-directed search for information, and therefore presented a negative view of their abilities. Despite this, Eddie reported that support should be developed by healthcare professionals, suggesting a preference for the traditional balance of power. In contrast, Lynn reported a positive relationship with a healthcare professional, citing regular communication facilitating as collaborative approach to caring for the care recipient. Lynn credited this professional for encouraging her to consider her own health and directing her to carer-focused support, stating that these needs would have otherwise been neglected. However, when describing the impact of web-based resources, Lynn reported increased empowerment but limited influence on subjective perceptions of health. She appeared surprised that there was limited web-based information for carers provided by the NHS. Rosa contrasted this view and reported positive benefits on health following interaction with web-based forums, such as increased understanding of her son's experiences and reduced isolation.

Empowerment through knowledge reported that carers utilised a needs-based approach to information seeking. Supportive needs changed throughout the caring role in accordance to situations encountered and the care recipient's health. Web-based information could be presented via different mediums, such as text, video, forums or live events. Suggested topics included information about schizophrenia, such as diagnosis or treatments, and carer health and caring entitlements. Due to the self-directed approach to information seeking, carers may fail to access useful information. Therefore it is important to minimise gaps in knowledge due to the potential implications for carer and care recipient health. Professionals argued the importance of providing reliable and quality information with the majority demonstrating concern that some carers may be unable to identify low-quality content. However, one carer argued that a resource should provide multiple perspectives as opposed to a medicalised approach. Finally, participants emphasised the need to provide realistic hope to carers.

Carer needs regarding situations encountered within the caring role has already been specified within this section. Lynn reported that management of these situations has resulted in the disregarding of information regarding the illness, such as suggested causes. Despite this, participants noted the value of information about schizophrenia. Eddie and Rosa reported accessing information through different mediums such as web-based forums, videos and lectures from universities. Eddie reported concern regarding the

quality and bias of some web-based resources, highlighting lectures provided via universities or content by drug companies.

Finally, carer and care recipient wellbeing and QoL has been proposed as an outcome derived from usage of the web-based intervention. This indicated that the receipt of knowledge and empowerment in the caring role could improve carer emotional health. The relationship between carer and care recipient health was outlined in individual interviews and depicted in Figure 4.7. This relationship indicates that improving carer health may also indirectly impact care recipient health.

The impact of web-based resource access on carer health, as measured by health questionnaires, has been presented in the previous chapter. Web-based resource use resulted in a reduction in anxiety, and increased wellbeing and QoL. Rosa attributed the use of web-based forums to health promotion, such as reduced isolation and increased understanding. She stated that web-based information enabled her to develop knowledge and accept the situation and diagnosis. Similarly, Eddie reported that web-based information was useful in the development of knowledge, however did not refer to any subsequent effect on health. In contrast, Lynn reported limited impact on health despite increased empowerment following receipt of web-based information. Lynn and Eddie stated that they believed their health could only be improved with another individual undertaking the caring role or the recovery of the care recipient. None of the carers used as illustrative examples directly referred to an impact on the care recipient's health, although Rosa stated that receipt of information through web-based forums improved communication.

The above section has briefly outlined the key elements of the CNAF towards the construction and evaluation of a web-based intervention and has presented these key elements with illustrative examples from the carer sample. The following sections will further examine these elements in relation to previous literature identified within Chapter two: background literature.

5.2.3 Personal preference: Considering the accessibility of the internet

As depicted in figure 5.1, there are 5 key considerations for resource developers relating to Personal preference: Considering the accessibility of the internet. These consist of;

- Accessibility of web-based resources through multiple devices.

- Information presentation and avoidance of surplus.
- Provision of understandable information.
- Consideration of individual needs and recognition of choice concerning resource access.
- Consideration of key barriers to web-based support access.

As noted in the introductory chapter, access to the internet has increased exponentially, with recent figures indicating that 90% of UK households had access to the world wide web (Office for National Statistics, 2018). This figure is likely to increase with the development and availability of devices allowing internet access, and with the increased focus of technology in healthcare (NHS Long Term Plan, 2019). Recently, the Department for Digital, Culture, Media & Sport (DCMS) has stated the aim of reducing the digital divide by increasing minority access to the internet, for instance individuals who are homeless or have a mental illness (DCMS, 2017). This report pledges to invest £1.1 million through the NHS to assist digital inclusion. All carers participating in the research informing this thesis had access to the internet via computers or smartphones. Only one carer did not own a personal computer, however they reported regular access through their local library. Participants praised the accessibility of web-based resources, supporting previous research (Lal et al*.,* 2017*;* Naslund et al., 2016; Sin et al., 2018).

Concerning increasing accessibility to the internet due to available devices, there appears to have been limited research investigating the impact of a carer-focused mobile phone app. Only two previous web-based interventions facilitated access through alternative devices, however it is important to note that this resource was not specifically developed for this purpose. For example, the intervention appeared to be designed for computer access but was considered mobile friendly (Stjernswärd and Hansson, 2017a; Sin et al., 2019b). Gleeson et al. (2017a) proposed a trial for a web-based intervention which incorporates mobile phones as part of data collection. Carers will complete surveys provided through a mobile phone app to assess stress. This could indicate scope for future research, supported by participant perceptions of increased accessibility and privacy of mobile phones.

Despite acknowledging the importance of information on carer empowerment and management of the caring role, participants reported the need to consider information presentation, understandability and avoidance of surplus information. Participants reported the need for an appropriate level of information, with some suggesting a layered

approach where the individual could indicate further content. The understandability of information in terms of carer-provided content and literacy levels will be outlined elsewhere in this chapter. Previous research has assessed the usability and understandability of web-based interventions alongside health and knowledge-based outcomes. For instance, Rotondi et al. (2010) found that a third of family members reported difficulty understanding information. As this intervention was underpinned by a model to overcome cognitive challenges associated with schizophrenia, this could indicate an inability to address carer needs. Alternatively, Sin et al. (2013) reported that siblings found the web-based intervention suitable in terms of information coverage, language use and quality.

Participants highlighted the value of a person-centred web-based intervention that could relate to their specific situation. On a basic level, this could relate to carers of individuals with schizophrenia or psychosis as opposed to carers in general or mental illness as a whole. On a higher level, an intervention could be tailored to the care recipient's specific needs or symptomology. This could provide carers with support regarding expected situations likely to be encountered in the course of the caring role. The literature review has highlighted difficulties in achieving person-centred information relating to confidentiality issues and the requirement for permission from the care recipient (Dirik et al., 2017; Cree et al., 2015). However, previous research has provided information to assist carers in tailoring content to their needs, such as obtaining key questions for subsequent information seeking (Lobban et al., 2013). Similarly, Roddy et al. (2015) assessed a needs-based intervention for carers, finding a reduction in carer distress and depression. Carers reported satisfaction with this approach to support provision. A further solution for providing person-centred support could be the inclusion of a needs-based algorithm or directions from healthcare professionals. These components will be considered in more depth later in this chapter.

Personal preference: Considering the accessibility of the internet also referred to individual choice regarding web-based support access. In terms of choice regarding web-based features accessible on an intervention, this is easy to achieve by providing an open platform. This supports previous web-based interventions that provided content through a website, therefore facilitating user choice in accessing features (e.g. Rotondi et al., 2005; 2010; Glynn et al., 2010). However, participants indicated that web-based interventions should be an optional means of support with the availability of non-web-based resources if preferred. This could be difficult to achieve due to macro influences, for instance the

transition towards digital healthcare and the promotion of self-directed information searching (for instance, Long Term Plan, 2019; Mental Health Taskforce, 2016; DoHSC, 2017a; 2017b).

There were two key barriers to web-based access reported by participants; digital literacy and age. Participants outlined the difficulty accessing web-based resources, reporting that this occurred regardless of prior experience with technology. Referring to digital literacy and usability, Szalma, Hancock and Hancock (2008) described technology as one of the "clearest paradoxes of modern work" (p56). For instance, computers were designed to facilitate task completion, however could become a barrier due to limited technological literacy or poorly-designed systems. Consequently, this can impact usage and subsequently effect health. Policy documents have considered the digital divide in the provision of technology and healthcare (DHSC, 2018a). The DCMS (2017) stated the aim to improve digital skill development to increase access to the internet. However, this appears to assume that carers, patients and professionals are willing and would like to engage in web-based support.

Participants indicated that reluctance to engage in web-based resources, and difficulty accessing this, is likely to be a short-term problem with the assumption that younger individuals were more confident using technology. Previous research has highlighted the link between age and technology usage, with younger individuals being more likely to access web-based resources compared to older generations (Blackburn et al., 2004; Read and Blackburn, 2005). These authors also found that age was associated with low technological literacy and complications using web-based resources or finding information. This assumption is interesting given the average age of the carer sample, as they were older but still appeared confident using technology. This could indicate the need to be aware of absolute assumptions, relating to what Heyman and Henriksen (1998) classified as an ecological fallacy. These authors stated:

> *'In foggy temporal conditions, individuals will tend to detect the outlines of futures which their cultural background leads them to expect. They can then obtain probabilistic evidence which may support their position. Falsification depends on demonstration of the superiority of an alternative predictive grouping. Established risk heuristics may be difficult to dislodge because they work well enough with populations, and no probabilistic prediction, by definition, can anticipate individual outcomes with perfect accuracy.' (p74)*

Hill and Machin (1998) further discussed blame, stereotypical perceptions and attribution of risk to ethnic groups, using an example of a maternity ward settings. For instance,

stereotypical views and generalisations regarding length of labour were placed on ethnic minorities, which are based on generalised facts despite evidence indicating the contrary. In relation to the research informing this thesis, recent figures state that the older demographic continue to have a lower rate of access compared to other age groups (Office for National Statistics, 2018). However these statistics acknowledge a gradual increase of older individuals using the internet.

5.2.1.1 Summary

The element of personal choice: considering the accessibility of the internet in the CNAF aims to promote accessibility of web-based resources and construct a person-centred form of carer support. Operationalisation of the CNAF could allow access through multiple devices in accordance to personal preference or device ownership, such as access through mobile phones and computers. The ability to access web-based resources could promote engagement and personal choice. The CNAF further promotes carer autonomy in supporting choice and access. For instance, given the availability of web-based resources, carers can choose to access these in accordance to their needs. Additionally, an unscripted web-based resource can provide access to appropriate components or content relevant to the carer's situation.

Understanding key barriers to web-based resource access can facilitate solutions to overcome these and, as a result, increase access. One example barrier to access is the care recipient preventing carer access to support. Participants indicated that support accessible through smartphones could promote privacy and allow quick access to support. Participants suggested that information surplus was a key barrier to resource access; and one solution could be the presentation of information within tiers. This could facilitate carer understanding and provide the ability to seek further content, if relevant to the individual carer situation. In doing so, this can promote person-centred support relating to needs encountered within the caring role. Additionally, the provision of easily-understandable information and the absence of medical terminology could be relatable to carers and aid understanding. This could further promote expertise via experience and aid collaboration with healthcare professionals.

5.2.4 The landscape of carer support

Key considerations of the landscape of carer support are as follows:

- Consideration of the evolution of technology.
- Negative appraisal of web-based resources.
- Referral to alternative resources.
- Provision of support specific to diagnosis and carer circumstance.
- Consideration of financial restraints.
- Consideration of privacy.

The evolution of technology was considered by participants, for instance the increasing availability of web-based information and sharing of events and content. This perception of technology appears to be supported by figures presented by the Office for National Statistics (2018) which indicate increased internet access.

Participants displayed a negative appraisal of web-based resources; while professionals reported concerns relating to quality, remoteness and impact on services. These concerns were also reflected within previous literature, which included the perception of web-based resources as an unwelcome extension to professionals' duties (Berry et al., 2017; Clarke et al., 2017; DoH, 2014). Vis et al. (2018) reported that negative attitudes towards eMental health web-based resources could inhibit effective implementation in healthcare. Therefore, there could be a need to consider the implementation of web-based resources into healthcare provision. For instance, normalisation process theory (NPT) focuses on the implementation, embedding and integration of interventions into healthcare practise (May and Finch, 2009). Murray et al. (2010) argued the enduring effectiveness of an intervention is contingent on uptake and implementation in organisations. NPT proposes four components to normalisation; coherence, cognitive participation, collective action and reflexive monitoring. Coherence denotes to the singularity of the intervention and user sense of purpose. Cognitive participation denotes perspectives of the population and likelihood of using the intervention. Collective action is indicated by compatibility of the intervention with practice. Finally, reflexive monitoring is the perception of the intervention ensuing from initial use. Based from reflection on this theory and research findings, the implementation of web-based resources requires a change in cognitive participation and collective action. Failure to consider implementation of the web-based resource could influence adherence and the subsequent effect on carer and care recipient health.

Despite this, Dohery et al. (2010) suggested that healthcare professionals reported acceptance of web-based resources whilst also acknowledging concerns regarding privacy and professional responsibility. It could be difficult surmounting these concerns. Whilst the provision of evidence-based information could meet quality requirements, the impact on non-web-based services is outside the scope of the developer. Tentative actions could include the inclusion of a referral feature on the web-based resource (such as that included by Glynn et al., 2010; Lobban et al., 2017) to promote existing services, or collaboration with services towards intervention construction (see later in this chapter).

A web-based intervention could increase carers' access to support, providing rapid access to information and communication when encountering a stressful situation. Participants reported a requirement for specific information relating to their situation and circumstances. Kuipers et al. (2010) proposed a model for support based on considerations of the carer's appraisal of schizophrenia and their relationship with the care recipient. For instance, carers who reported a positive relationship with their relative and demonstrated an affirmative appraisal of psychosis are likely to require some support. In contrast, an individual with a strained relationship with their relative and a negative appraisal of psychosis, such as those indicating high levels of EE, would require more intensive support. Concerning resources specific to carers and diagnosis, literature has considered the limited available support that solely focuses on carer needs (Kuipers, 2010; Onwumere and Kupers, 2017). These authors attribute the lack of carer-focused resources in healthcare to austerity and strained resources. Difficulty acquiring funding could pose a significant barrier to the construction of a carer web-based intervention. These barriers also relate to carers' financial situations, with costs relating to purchasing of technology, updates and software. One suggestion could be a carer assessment which could provide funds and facilitate access to technological devices.

5.2.2.1 Summary

The CNAF fulfils the element of the landscape carer support by considering the negative appraisal of web-based resources. The use of an initial assessment can present the opportunity to address any immediate concerns and encourage access. It could be valuable at this point to promote the advantages of web-based support, such as access to support at any time. The negative appraisal of web-based resources appears to be focused on the provision of this as a singular source of support. Participants reported concerns of web-based resources resulting in the reduction in non-web-based services. One solution could be the ability to refer carers to alternative organisations and web-based resources to seek

further content and support relating to their situation. This component could also promote personal choice in supportive access. Additionally, collaborating with carer services and professionals, such as involvement in the construction and maintenance, could further reduce the negative appraisal of web-based resources.

The CNAF provides specific needs-aligned support to carers of individuals with schizophrenia. The proposed CNAF outlines the relationship between knowledge and carer and care recipient wellbeing. This framework also proposes the value of a communication component in the provision of advice and receipt of understanding with individuals with similar experiences. Further specificity could be achieved with additional collaboration with healthcare professionals who could refer carers to content relevant to their situation. This will be considered in more depth later in this chapter.

5.2.5 Connection, understanding and advice online

There are six key considerations for resource developers regarding connection, understanding and advice online. These are as follows:

- Importance of providing an opportunity to communicate to other carers to share experiences and advice.
- Ability to passively interact with forums.
- Opportunity to develop an understanding of care recipient's experience.
- Importance of humanising web-based resources and the use of technology to promote this.
- Consideration of risks.
- Moderation.

Participants identified the value of web-based forums in facilitating information sharing and noted the value of communication with others experiencing similar situations in increasing understanding and reducing isolation. Previous literature has considered the impact of web-based and non-web-based forums on carer health. For instance, participating on a web-based forum could reduce carers' levels of isolation, and increase hope whilst also allowing the ability to share advice and direct to alternative resources (Perron, 2002; Haker et al., 2005; Trondsen and Tjora, 2014; Widemalm and Hjorthag, 2015). Within their model for a web-based intervention for individuals with FEP, Lederman et al. (2014) proposed the promotion of discussion between users to increase

understanding of the illness. Relating to carers, this could focus on developing an understanding of the care recipient's experiences. Lederman et al. continued to note the importance of safety and privacy to promote anonymity. This is supported by previous research which reported the benefit of communication with others or passive interaction with forums (Sin et al., 2018; Perron, 2002).

Participants noted that use of web-based forums could provide increased understanding of the care recipient's experience. With regards to previous literature, Rotondi et al. (2010) investigated the impact of a web-based intervention that included a forum for individuals with schizophrenia and their family members. Whilst this did not measure impact on understanding, the opportunity for communication with individuals with schizophrenia could be invaluable for carers. Alternatively, the inclusion of stories written by individuals with schizophrenia could increase carer understanding of the illness and their relative's experiences. However, one carer highlighted difficulties of a joint forum, such as an individual with schizophrenia posting whilst unwell.

Web-based interventions were critiqued by participants for a lack of humanisation and perceptions of remoteness in usage. Technological mediums such as Skype or FaceTime, where individuals in different locations can interact with each other in real time, could increase personal connection within a web-based intervention. However, it is important to note that security procedures could reduce perceptions of the humanness of a web-based resource. Users are encouraged to preserve confidentiality by using a pseudonym or avoid use of identifiable content. One suggestion could be providing carers support via a live stream; i.e. presenting a psychoeducational intervention in one location whilst streaming to an external location (Hayley et al., 2011). Although this could increase humanness of a web-based intervention, provision of support in this format would be restricted to a specific time. This could indicate the inability to revisit content or refer to during situations encountered in the caring role.

Negative appraisals of web-based resources were influenced by concerns regarding risks for user safety and privacy. Whilst posting about experiences could be beneficial for individuals, the risk of over disclosure and the implications associated with this increases negative appraisal of web-based resources. Whilst the privacy of the resource could be considered within the construction of a web-based resource (for instance, the inclusion of usernames or sign-in options), the autonomy of users could pose a risk to their and care recipient confidentiality. Perron (2002) found that disclosure was the most prevalent mechanism displayed on a web-based chatroom for carers of individuals with mental

illness. Disclosure included regular updates and description of events encountered throughout the caring role. Whilst disclosure could be beneficial for carer health, for example in reducing isolation, there remains a risk of over disclosure regarding carer and care recipient identity and safety. Participants appeared to associate over disclosure with carer distress, however literature has suggested the impact of the disinhibition effect. Suler (2004) defined this as the over sharing of personal information via technological interfaces, in which he reported the significant influence of individual differences on possible disclosure. Suler went on to outline dissociative anonymity as one of the causes of over disclosure, describing this as the user's perception of anonymity increasing oversharing of information. However, Barak et al. (2008) suggested that over disclosure provided a prospect for self-exploration and an opportunity to work through issues.

A further concern of web-based communication includes the inability to view facial cues, resulting in difficulty understanding meaning and increasing possible misunderstanding relating to content or intent of the communication. Mohr, Cuijpers, and Lehman (2011) reported the impact of this barrier on supportive accountability, however they also noted that this could depend on bandwidth and available internet connection. Mohr et al. further stated that these barriers would reduce with increased internet access, leading to increased connectivity, and continued adaptation of language to convey information in text-based communication such as the use of emoticons or GIFs to portray emotions or intent. Again, one solution to the difficulty establishing meaning from web-based communication is the incorporation of video streaming or video calls (such as Skype or FaceTime). However, the use and quality of these can vary in accordance to connectivity. Despite the increasing connectivity and speed of the internet, it is important to note that these factors presently remain a significant barrier in some areas of the UK. The HOC (2018) reported that 93.5% of UK premises have access to superfast broadband, indicating easily access to the internet, web-based videos and downloadable content. The UK Government classifies superfast broadband as higher than 24 Mbps with 10 Mbps being considered an adequate internet speed. The HOC notes that 2.4% of the UK have limited connectivity (below 10 Mbps), indicating difficulty accessing and utilising web-based content. This could suggest further difficulty accessing web-based resources including videos and live communication components.

Risks, such as over disclosure, denote the requirement for moderation or considerations to minimise such issues. Example solutions could include providing reminders relating to confidentiality or the use of moderation to mitigate risk of over disclosure. Previous

research assessing carer web-based interventions have provided moderation. For instance, Lobban et al. (2017) proposed supportive staff moderating the resource during working hours, however this indicates that this moderation is not available outside this time. In contrast, Gleeson et al. (2014) provided a separate communicative system for moderators for a web-based intervention for individuals with FEP. Moderators also had the ability to suspend accounts of inappropriate conduct. Moderation will be further considered later in this chapter.

5.2.3.1 Summary

Implementation of the CNAF can assist in the construction and evaluation of web-based resources in maximising users' effective communication, connection and understanding. The inclusion of web-based forums within the CNAF can provide the ability for carers to interact with others in similar situations and therefore reduce isolation. Utilising forums can increase understanding and facilitate sharing advice relating to situations encountered in the caring role. Whilst web-based forums can provide interactive support, the availability of posts can allow passive engagement or lurking. The opportunity to interact with individuals with schizophrenia and psychosis can increase carer understanding of their relative's experience. This understanding can influence interaction and management of the caring role and, as a result, influence care recipient health.

By considering and promoting the humanising of web-based resources, this can increase usage and understanding. Examples of humanising web-based forums include personal stories, Skype and video chat, which allow communication with a human presence. This could overcome a major critique associated with web-based resources, that being remoteness of support, which is particularly important given the reported isolation of carers.

The connection, understanding and advice online element of the CNAF acknowledges the importance of moderation in reducing risk. Examples of risk in web-based forums include over disclosure and possible conflict or negativity. However, the CNAF also notes the implications of this in the power balance of healthcare relationships.

5.2.6 Expertise via experience

Key considerations for research developers for expertise via experience consist of:

- Knowledge developed via managing the caring role and the importance of sharing this with carers beginning this role.
- Importance of providing comprehensive information to increase carer empowerment.
- Importance of providing information relating to situations encountered in the caring role.
- Difficulties between carers and professionals – influence of this on directing to resources and the importance of providing multiple perspectives.
- Importance of promoting carer self-care.

Prior to their relative's FEP, carers reported limited knowledge of psychosis or interaction with mental health services, resulting in information-seeking. Participants reported acquiring knowledge through experience undertaking the caring role, thus indicating experiential learning (Kolb, 2015). This supports Heyman's (1998) proposal of honorary experts; individuals offering personal knowledge about their relative in a healthcare setting, and the subsequent transition towards collaborative care. Collaborative-based care has resulted in an increased focus on incorporating carer and patient views towards treatment and service provision (Mental Health Taskforce, 2016; Worthington et al., 2013; DoHSC, 2018a; 2018b). Whilst previous research has reported that carers and professionals found a collaboration approach to be mutually beneficial (Cree et al., 2015; Bradley and Green, 2017; Stanbridge 2012; Susanti et al., 2018), the present participants reported difficulty receiving information from professionals and a preference for the traditional balance of power in healthcare.

The ability to eliminate the power imbalance within a healthcare setting has already been considered earlier in the research underpinning this thesis. Despite an attempt to increase collaboration with service users and carers, it could be argued that healthcare professionals remain in a more powerful position. Prior examples include detainment under The Mental Health Act (1983), which includes therapeutic treatment to individuals judged to have limited capacity. This could also relate to the concept of moderation within web-based forums. Whilst the merits of moderation are clear in terms of reducing risk, this could result in increased power for healthcare professionals completing this task. One recommendation could be the inclusion of carer moderators (for example Lederman et al., 2014), however this could require regular assessment of the carer's ability to complete this role alongside their fluctuating caring role to minimise increased stress.

Participants reported a need for information regarding situations encountered within the caring role, thus supporting previous research (Lloyd and Carson, 2005). Receipt of this information was perceived to increase carer empowerment. Whilst this can clearly be beneficial to the caring role, one concern could be the expectation of a correct way to respond to situations. Although there are recommended practices regarding the treatment of schizophrenia, this advice will continue to be developed over time, resulting in the risk of individuals following out-dated advice. Thus, advice would need to be updated in accordance to recent guidance. Further concerns relate to an inability to locate clear guidance as this could increase carer distress, hopelessness and anxiety; all of which could be further increased if the information found is perceived to be ineffective. This could also indicate the need to provide up-to-date information and encourage carer engagement with this to minimise risks of following outdated advice.

Participants reported limited support through services, with one professional querying the appropriateness of informational content produced by healthcare professionals. This participant indicated that information solely provided by professionals could prevent carer adherence, supporting prior research (Lloyd and Carson, 2005). The tensions between carers and healthcare professionals has been documented within previous research, for example Onwumere et al. (2016b), Sin (2013) and Wainwright et al. (2015). However, carers disagreed with this view and cited a preference for the traditional balance of power. This could indicate the importance of including both professional- and carer-developed content to increase accessibility and adherence by users. Previous web-based interventions have included carer and care recipient stories or videos to increase understanding and engagement with the web-based intervention (Chan et al., 2016; Lobban et al., 2017). The inclusion of personal stories could raise confidentiality concerns, increasing the risk of individuals being identified through experiences or video. One solution could be including actors to represent carer experiences, however clarity of portrayals would be required to increase trustworthiness.

Carers of an individual with mental illness have focused on the needs of the care recipient due to the belief this would improve their own needs (Askey et al., 2009; Murray, 2018). Stjernsward and Hansson (2017a) reported that following encouragement to consider personal needs, carers acknowledged the value of increasing their own health and indicated this influenced their response to situations. Therefore, one suggestion for overcoming this issue could be the involvement of a blended intervention: non-web-based support directing carers to a web-based resource. For instance, a carer could be directed

to appropriate sections of the web-based resource following initial assessment by a healthcare professional. In this sense, the web-based intervention could be an additional advantageous tool to facilitate support sessions and for use outside of available hours. Alternatively, a web-based mechanism such as an algorithm could direct carers to content based on their needs. The web-based algorithm will be considered in further depth later in this chapter.

5.2.4.1 Summary

The CNAF acknowledges the experiential knowledge that carers develop over time when managing the caring role. Subsequently, the CNAF provides the ability to share advice and experiences with other carers via web-based forums and collaboration with carers to provide informational content. Whilst beneficial to all carers, this is particularly useful for carers beginning a caring role. The inclusion of information and perspectives from carers and individuals with schizophrenia can promote collaboration. This can promote engagement and interaction with web-based resources if carers are experiencing difficulties with healthcare professionals.

The provision of comprehensive and balanced information can assist carers in management of the caring role. Information from multiple perspectives encourages carer autonomy and the ability to make up their own mind. Furthermore, information regarding situations encountered in the caring role can increase carer empowerment and control. The provision of this can place carers on an equal power footing to healthcare professionals.

5.2.7 Empowerment through knowledge

Empowerment through knowledge consists of 6 key considerations for designing a web-based resource for carers of an individual with schizophrenia:

- Carers utilising a needs-based approach to web-based support seeking, and awareness of changes associated with needs.
- Presentation of information via different formats or mediums.
- Providing detailed information regarding schizophrenia and carer emotional-focused support and caring entitlements. Ensuring access to minimise gaps in knowledge.
- Providing realistic hope.

- The importance of reliable and quality information and awareness of potential difficulties determining quality.
- Providing multiple perspectives as opposed to medialisation.

Empowerment through knowledge discusses carers' search for information, supporting previous research (Kuipers, 2010b). Participants reported the need for web-based information regarding the caring role, schizophrenia and psychosis, and professionals. Previous research has highlighted carers' needs for information regarding the illness following initial diagnosis and the impact of technology on independent support seeking and empowerment (Kuipers, 2010; Outram et al., 2015; Sustanti et al., 2018; Onwumere et al., 2011; Berry et al., 2017; Lee and Scheep, 2013). Thus, this supports Eysenbach and Jadad (2001), who proposed that following the introduction of web-based information users are placed on an equal footing with healthcare professionals. However, whilst these authors suggested that this may be perceived negatively by professionals, this was not reported by the present sample. Despite some concerns regarding web-based resources, professionals appeared to have a positive view of and promote carer empowerment and information acquisition.

As previously noted, carers reported implementing a needs-based or problem-solving approach to searching for web-based support regarding symptom and situational management. D'Zurilla and Goldfried (1971) defined problem-solving as a behaviour in which an individual attempts to locate solutions to a difficult situation. However, these authors acknowledge the possible discrepancy between problem-solving and implementing a response to the perceived problem. The stress, appraisal, coping model proposes that the appraisal of a stressor can result in two coping mechanisms; emotion-based or problem-solving coping (Lazarus and Folkman, 1984). A problem-solving coping method is an attempt to alter a stressful environment, for instance searching for web-based information (Folkman et al., 1986; Folkman, 2008). Folkman and Greer (2000) suggested that greater perception of control over the situation resulted in higher levels of problem solving in individuals with a serious illness. The inclusion of a problem-solving approach has been included within previous web-based interventions for carers (see Glynn et al., 2010; Chan et al., 2016; Lobban et al., 2018). Acquiring this information could influence appraisals of the caring role, schizophrenia and psychosis, and carer supportive resources.

Providing information via various formats, such as video or images, and the inclusion of multiple perspectives, can increase interest and engagement with a web-based resource. This can also increase accessibility to content if carers struggle with written text due to literacy levels or disabilities, for example dyslexia. Additional considerations concern the quantity of text, with information overload preventing usage; a new issue for Human Computer Interaction (HCI) (Grudin, 2008). One example could be including a stepped-based format where initial information is provided, and the user indicates the amount of further content received. Alternatively, the use of video can portray information in a more accessible method to written text. For instance, Chan et al. (2016) and Glynn et al. (2010) investigated the impact of a web-based intervention for carers which incorporated streamed or YouTube videos in addition to written information.

Participants expressed the importance of incorporating information provision with the construction of a web-based resource for carers, with participants identifying gaps in knowledge. Example topics included information about schizophrenia, available carer support and entitlements or benefits. This supports previous web-based interventions which have included psychoeducation components (for example, Rotondi et al., 2010; Glynn et al., 2010; Lobban et al., 2017). This finding indicates carers are seeking information regarding the caring role, aligned with previous research (for example, Onwumere et al., 2011). The impact of information on carer empowerment will be considered in more depth within the following section.

Quality was a significant element raised in professional interviews, including concern regarding the quality of existing web-based information. Eysenbach and Jadad (2001) noted that professionals were no longer the filter to information and therefore service users could be vulnerable to incorrect information online. This model assumes that professionals have technological skills and digital literacy to guide service users. Previous research supports participants' concern regarding carer ability to determine the quality of web-based information (Berry et al., 2017; Gleeson et al., 2014; Naslund et al., 2016). Recently, there has been increased concern regarding fake content on the internet, with focus placed on fake news. Analysing content relating to the USA election, Allcott and Gentzkow (2017) found that fake news favoured Donald Trump, finding one website, which was rated at 50% accuracy, receiving 159 million visits during the election month. The Digital, Culture, Media and Sport Committee (2019) attributes the increased prevalence of fake news to social media, resulting in a focus on clarity of web-based information and the limitation of technological companies' expansion. There appears to

be an assumption that carers would be able to identify evidence-based information and misinformation. Whilst the present carer sample appeared to be confident and proficient in identifying quality resources, accessing inferior resources could cause distress. Further concerns relate to carers misinterpreting or failing to follow current recommendations regarding treatment for the care recipient.

Participants identified the importance of increasing hope and reported feelings of hopelessness associated with the caring role, supporting previous research (Onwumere et al., 2016b; Wainwright et al. 2015). Web-based resources, such as forums, have reported a positive impact on carer hope and a reduction in isolation (Trondsen and Tjora, 2014; Widemalm and Hjorthag, 2015). Whilst this supports the findings of the research underpinning this thesis, participants noted the importance of realistic hope. One example of promoting realistic hope relates to psychosis recovery rates. Participants noted the importance of encouraging hope in carers which could be transferred to the care recipient. The provision of unrealistic hope and expectations could led to the carer experiencing distress and frustration at a later date.

The inclusion of carer and care recipient views has already been discussed within this chapter and will not be revisited here. Additional contrasting perspectives could include content from different disciplines, for instance a CBT therapist perspective of treatment included alongside a psychiatrist. Alternative views to the medical perspective include theories provided by Szaus (1988) and Foucault (1967). These viewpoints could be useful to include in outlining the history of mental illness and acknowledging the antipsychiatry movement. However this could increase carer distress and have ramifications relating to the care recipient accessing treatment.

5.2.5.1 Summary

The CNAF identifies the importance of knowledge in the development of carer empowerment and the resultant impact on carer and care recipient wellbeing and QoL. First the CNAF recognises the carer application of a needs-based search for web-based support and information. In doing so, this incorporates information relating to practical and theoretical content whilst also providing a communication aspect. The availability and range of content could continue to fulfil carer fluctuating needs throughout the caring role.

The CNAF highlights the importance of high-quality information to promote carer hope, understanding and empowerment. Whilst the CNAF acknowledges the importance of hope promotion, this also advocates realistic hope relating to treatment and recovery. Information components often focus on written content, however they can incorporate content through web-based forums, live events and videos. The provision of information via multiple mediums can promote engagement and personal choice in accessing support.

Regarding web-based information, the CNAF highlights the value of information provision regarding schizophrenia, such as theoretical explanations, diagnostic criteria and treatment. This framework further ascertains the provision of multiple perspectives as opposed to solely including a medicalised view, again increasing carer autonomy and choice relating to content. This framework recognises the difficulty encouraging carer recognition and consideration of their supportive needs. By promoting carer health, this could subsequently impact the health of the care recipient (see Figure 4.7).

5.2.8 Carer and care recipient wellbeing and QoL

Finally, there were two key elements relating to carer and care recipient wellbeing and QoL:

- The resulting impact on carer health following increased empowerment.
- The relationship between carer and care recipient health.

The findings of the research informing this thesis have suggested carers engage in a self-directed search for web-based information, which in turn can increase carer empowerment. These findings support previous research reporting the impact of web-based resources on user autonomy (Berry et al., 2017). The importance of information on carer empowerment has been considered throughout this thesis, for example the development of knowledge to facilitate dialogue with healthcare professionals (Lal et al., 2017). Evidence for impact of knowledge and empowerment on carer health as a result of participation with web-based interventions appears to be mixed. For instance, carers or family members have demonstrated increased knowledge but reported minimum impact on health outcomes (Rotondi et al., 2005; 2010; Sin et al., 2013; Chan et al., 2016). In contrast, Stjernswärd and Hansson (2017a) found that participating in a mindfulness web-based intervention resulted in a reduction in perceived stress, and increased mindfulness, self-compassion and QoL. One suggestion for the improvement in carer health could relate to the primary focus on carer health, as opposed to also incorporating

this content with information concerning mental illness. This could indicate the importance of encouraging carers to consider their supportive needs alongside the care recipient's health, noted as a key barrier by participants.

Whilst the above framework focuses on the positive impact of empowerment on carer health, it is important to consider possible negative implications. For instance, whilst one carer credited web-based resources for increasing empowerment, she noted that this did not impact on health. This perspective was supported by Absalom-Hornby et al. (2012) who found an increase in carer's fear for the future and sorrow following the provision of information about schizophrenia, which the authors attributed to an increased understanding of the expected impact of the illness. This indicates the importance of promoting hope with information provision to reduce potential negative effects on carer health.

The relationship between carer and care recipient health has already been considered in depth earlier in this thesis and depicted in Figure 4.7. This relationship is supported by previous research, for instance a CBT-based model proposing a relationship between carer and care recipient emotional responses to the other party's behaviour (Lobban and Onwumere, 2016). Previous research into EE has also highlighted the relationship between carer health and care recipient relapse (Brown et al., 1962; Koutra et al., 2015; Jansen et al., 2015; Kuipers et al., 2006). This could indicate the value of a joint web-based intervention for carers and their relatives, however previous research has primarily focused on one party's health; for instance, improving the health of individuals with schizophrenia or their carers (Glynn et al., 2010; Lobban et al., 2017; Gleeson et al., 2017; Alvarez-Jimenez et al., 2019). Rotondi et al. (2010) investigated the impact of a web-based intervention on the health and knowledge of carers and individuals with schizophrenia. However, the model underpinning this web-based intervention focused on increasing engagement by individuals with schizophrenia (Rotondi et al., 2007), therefore may not be applicable to carer-focused needs.

5.2.6.1 Summary

The CNAF aims to improve carer knowledge, particularly surrounding situations encountered within the caring role, resulting in increased empowerment and control over the caring role. The relationship between carer and care recipient health (as depicted in Figure 4.7) suggests that by increasing carer knowledge and the ability to manage the

caring role, carer health can be impacted. The provision of high-quality information was noted to increase carer hope and understanding towards the care recipient's needs. Increased confidence in managing situations could impact on care recipient health.

5.2.9 Summary of Key elements of a carer needs-aligned framework

This section has presented the six key elements contributing to the CNAF for a web-based intervention. Three of these elements were considered fundamental prerequisites, while two were fundamental aspects contributing to the single outcome. These elements were outlined and related to three carers who participated in the research underpinning this thesis. Following this, the six elements were briefly discussed in relation to previous research identified within the literature chapter. The subsequent section specifies the overall considerations of the CNAF.

5.3 Overall considerations: A refined carer needs-aligned framework

This chapter now turns to overall considerations of the refined CNAF deriving from the key elements presented in Figure 5.1. As can be seen from Figure 5.2, there are ten components to consider for inclusion within a web-based intervention. As with Figure 5.1, carer knowledge and empowerment is considered to be fundamental elements towards carer and care recipient wellbeing and QoL. The intervention components could refer to fundamental prerequisites towards the development of empowerment and control. This section will briefly outline these components before discussing these in more detail. Although presented within a single image below, interventions are discussed in relation to overall and further tentative considerations.

The below figure illustrates carers accessing a web-based intervention. Potential carers refers to individuals seeking information regarding schizophrenia or psychosis prior to diagnosis or assessment. Receipt of information could provide an explanation to their relative's unusual behaviour and result in contact with healthcare services.

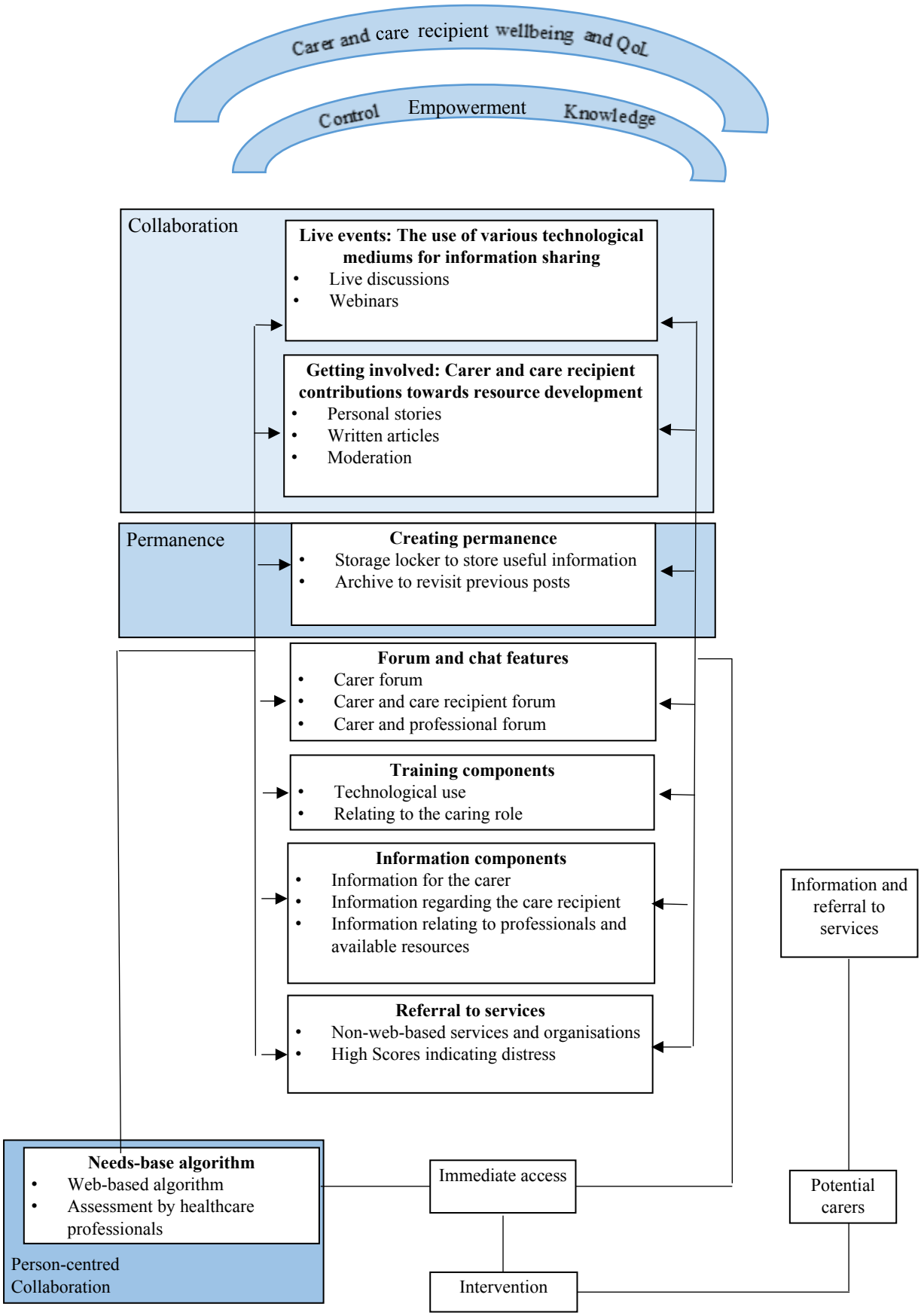

Figure 5.2 A figure presenting considerations in operationalising the CNAF.

The ten components of the framework will be briefly outlined below:

Needs-based algorithm: Carers could have the option to complete a needs-based algorithm on the web-based resource to indicate useful content relating to identified needs. For instance, this could include health questionnaires that would refer users to appropriate content based upon analysis of their needs. Thus, an algorithm could encourage carers to consider their supportive needs alongside the care recipients'. However, this should be an optional feature to minimise frustration when accessing the resource, particularly in the event of an emergency. Alternatively, a needs-based algorithm could relate to professional recommendations towards content based on assessment with carers. Therefore, this could promote a collaborative or blended approach incorporating web-based and non-web-based components. This supports previous research where professionals guide and support carers based on their needs, in some cases directing them towards an information website (Roddy et al., 2015).

Live events: The inclusion of live events could provide access to information via an interactive medium. For example, this could relate to live discussions between carers and healthcare professionals or could feature webinars presented by a subject specialist. Regular availability of live events could continue to promote ongoing adherence and usage of web-based interventions.

Carer and care recipient collaboration: Participants highlighted the importance of incorporating content created by the carer and care recipient to increase understanding and engagement with the resource. Further potential positive impacts on health included a reduction in isolation and increased hope. Examples of contribution by carers and care recipients include personal stories relaying experiences, written articles and the ability to assist in resource moderation.

Creating permanence: Whilst participants had indicated the creation of a web-based resource could designate permanence, this mechanism could be further enhanced via the creation of a storage locker or archive system. A storage locker provides users with the ability to save, and therefore quickly access, information applicable to their situation. An archive of previous posts, articles or training modules could facilitate access to previous content and therefore increase perception of permanence.

Forum and chat features: Examples of included forums are; carer-only forum, carer and care recipient forum, and carer and professional forum. This intervention component can facilitate communication between individuals with similar experiences and could therefore reduce isolation. The availability of a web-based forum with individuals with

schizophrenia could increase understanding regarding the other party's experience. Additionally, forums with healthcare professionals could provide carers with expert advice relating to their personal situation.

Training components: Training components could relate to technology use, such as instructions regarding using or accessing the components of the web-based resource. Alternatively, this could complement the information components and provide content relating to the caring role or situations encountered.

Information components: This intervention component refers to the provision of information to increase carer empowerment and knowledge. Suggested content includes information for the carer (such as benefits and legal rights), information regarding the care recipient (for instance, aetiology and treatment), and information concerning professionals and available supportive resources.

Referral to services: Referral to services includes the provision of a directory to non-web-based organisations and services. Additional considerations relate to referral following a high score within the needs-based algorithm, indicating significant distress and risk in the carer or the care recipient.

Having briefly outlined the overall considerations for the CNAF, the following sections will discuss five of these components in more detail. The remaining five components will be considered further in tentative considerations.

5.3.1 Needs-based algorithm

The web-based intervention should include the algorithm as an optional feature and still ensure quick access to the content without completion. This could be important with frequent visitors or carers who are already aware of their supportive needs. An example web-based algorithm is presented in Figure 5.3 below.

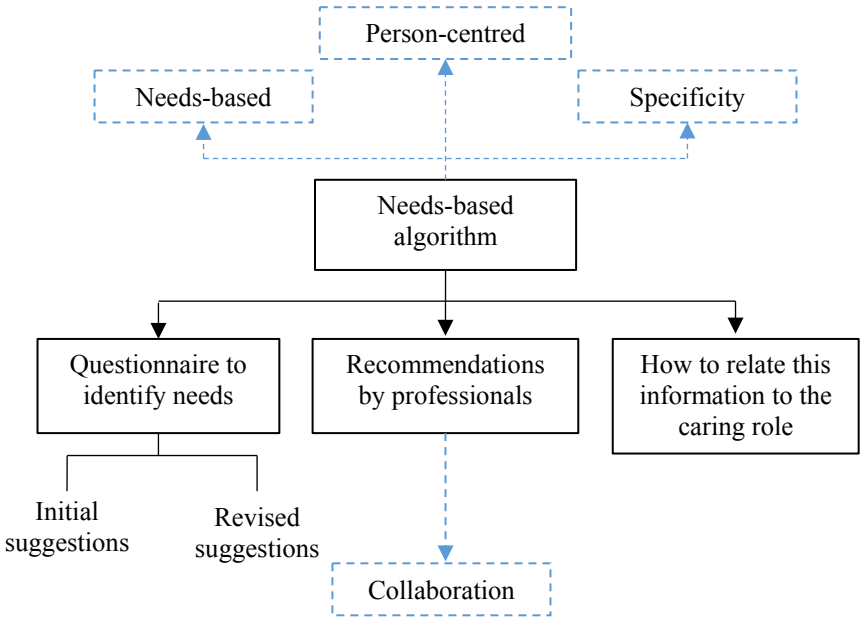

Figure 5.3 An example need-based algorithm for a web-based intervention.

As can be seen from the above figure, a needs-based algorithm could provide person-centred and carer specific support by referring to content based on supportive needs. For instance, an algorithm consisting of health questionnaires such as the HADS can direct carers to resources based on identified symptoms of depression or anxiety. As participants had indicated supportive needs could vary across the scope of the caring role, it would be valuable for the opportunity to revisit this component and receive revised suggestions. A further example could include content suggested by healthcare professionals who have assessed carer needs. This could indicate collaboration between carers and professionals and reduce potential relationship difficulties.

Finally, it could be valuable for suggested content deriving from the needs-based algorithm to refer to the caring role to provide clarity. For instance, examples of mindfulness techniques to reduce stress could be provided with content depicting situations likely to be encountered within the caring role. The reference to the caring role could assist carers in understanding content whilst providing an illustrative example towards use.

Whilst a strength of this feature is enabling a needs-based approach to support and information seeking, an algorithm could encourage carers' considerations of their own supportive needs rather than prioritising the care recipient. However this has several concerns, such as selecting questionnaires for inclusion and the ability to identify and provide an acceptable solution to carer needs. The algorithm could only consist of a small

number of health questionnaires to reduce risk of fatigue and non-completion. Therefore, questionnaires would need to be able to identify carer needs. Chapter three has considered the dissimilarity between quantitative and qualitative methodologies, suggesting that the latter approach may provide further depth. Despite this, a quantitative methodology can provide a quick and efficient method to establish suggested content based on identified needs. However, one risk could be the focus on aspects prevalent in policy, as opposed to concentrating on carer needs. Additional decisions include whether subsections of questionnaires are used to identify sections of the resource or whether this should prioritise total scores. For instance, AC_QoL has 8 subsections and a total score of QoL.

Regarding the ability to satisfy carer needs by directing them to appropriate resources, Mohr et al. (2011) stated that web-based resources should have the ability to address a problem while also offering a solution. To fulfil carer needs, an algorithm would be required to direct to practical and emotional information or support. For instance, scores indicating anxiety could be directed to information regarding self-care or basic mindfulness techniques (such as that provided by Stjernsward et al., 2017). Alternatively, carers reporting isolation could be guided to a web-based forum. However, there would need to be considerations regarding the occurrence of high or concerning scores achieved on a questionnaire. One option is to refer to appropriate services, for instance IAPT for high anxiety scores. Conversely, if scores indicate a safeguarding concern or crisis relating to carer or care recipient safety, the anonymity of web-based resources could create a significant barrier. Lobban et al. (2017) included a protocol within a proposal for a web-based intervention whereby low risk would be referred to crisis support whereas high risk resulted in contacting emergency services. Therefore, carer personal information would need to be collected, which could deter some users due to privacy concerns by the care recipient.

Further contemplations include the appropriateness of a web-based algorithm to identify carer needs. The detachment of web-based resources has already been considered in depth, however there is a debate regarding the appropriateness of an algorithm in identifying carer needs. One suggestion to fulfil carers' needs-based approaches to support seeing could be collaboration with healthcare professionals who could direct carers to relevant components of an intervention based on assessment of their situation. A similar approach was completed by Roddy et al. (2015); whereby carers were directed to resources based on their needs, including a website. However, completion of this

approach is dependent on care recipient acceptance of information sharing about their illness and carer willingness to be active agents in their relative's care.

5.3.2 Information components within the CNAF

The results chapter has introduced empowerment through knowledge as a dominant theme, indicating the importance of information provision on carer empowerment and its potential subsequent impact on emotional wellbeing. There appeared to be an expectation that carers would provide care for their relative and, as previously stated in the literature review, carers reported beginning a caring role with limited knowledge of mental health or schizophrenia, with this being developed based on experiences and observations (Onwumere et al., 2016a; Sin, 2013, Wainwright et al., 2015). This was reiterated by participants, with one carer undertaking a "crash course in psychiatry". Whilst carers could receive information via alternative resources, information components can provide quick access to content during an emergency or following a query. Previous web-based interventions for carers have supported this and included informational components (see for example, Lobban et al., 2017; Sin et al., 2015; 2019a; Rotondi et al., 2010). Examples of information topics provided by these interventions include stress management techniques, information about schizophrenia or psychosis, carer emotional wellbeing and situation management.

Participants suggested informational topics for inclusion within a web-based intervention that can be broadly defined into three categories; information for the carer, information regarding the care recipient, and information concerning professionals and available resources. Relating to information for the carer, participants identified the value of providing practical information, such as carer rights under the Mental Health Act (1983), carer assessments and benefits. An additional example of practical information included transitions during the caring role. For instance, one carer reported searching for information regarding future trust funds when they are no longer able to provide care. Participants noted that whilst this content may presently be available online, information dispersion, lack of centralisation, disparity between physical and mental health, and focus on the care recipient pose barriers to access. Failure to access this information could result in feelings of frustration and loss of entitled benefits to assist the carer in their role.

Further suggested content included information regarding expectations of the caring role, with participants noting the importance of providing an honest but hopeful disclosure.

For instance, this included providing a realistic expectation of available carer support outside of organisational hours without causing distress. Participants suggested the usefulness of carer and care recipient stories in hope promotion and the reduction of isolation. The inclusion of personal stories could influence carer appraisal of schizophrenia or psychosis (Lazarus and Folkman, 1984). For example, for new carers this could reduce previous preconceived notions of risk associated with mental illness. For long-term carers this could indicate recovery progress achieved over the course of the caring role.

The section focusing on information for the carer could provide content focusing on health promotion. For example, the inclusion of therapeutic content, such as CBT, could assist with a focus on symptoms of low-level anxiety or depression. Previous web-based interventions for carers of an individual with schizophrenia have included a CBT-informed approach, however the outcome on carer health is currently in press (Lobban et al., 2017; Sin et al., 2013; 2019a). An additional example could be the incorporation of mindfulness techniques, such as that provided by Sterjnsward and Hannson (2017). Previous literature has highlighted the impact of mindfulness on symptom reduction for anxiety and mood disorders (Hofmann et al., 2010).

Furthermore, one professional proposed the inclusion of a strength-based approach and acknowledgement of carer skills. Seligman et al. (2006) discussed the importance of promoting strengths and meaning within situations, arguing this could have an impact on health promotion and development of a future mental illness. Thus, Seligman et al. proposed exercises incorporated with therapeutic content, such as completing a pleasurable activity, or the identification of personal strengths and consideration of use in daily life.

Participants suggested including information regarding the care recipient, with proposed topics including general information relating to the illness and symptom management. This supports previous web-based interventions, for instance Rotondi et al. (2005; 2010). Example content included description and possible explanation of the condition, available treatments and benefits obtainable to the diagnosed individual. In doing so, participants suggested that this section included a range of perspectives as opposed to solely prioritising a medicalised view. For instance, carer, patient and healthcare professionals' perceptions of schizophrenia to promote understanding of care recipient's experiences.

In terms of possible information indicating contrasting expert opinions regarding schizophrenia or a psychosis disorder, there is a need for balance between the information needs of carers and the possibility of confusion or distress. Whilst there is an ongoing debate regarding this, one point of note is that different theories are already available via the internet. The proposed web-based intervention could provide links to external sources for carers to access if they chose to do so, however perhaps the guiding principle should focus on the manifestation of specific issues which need to be dealt with and practical strategies.

Finally, an informational component concerning professionals and available resources could include topics such as professional roles and responsibilities towards carer and care recipient care. Provision of this information could reduce carer frustration with services by providing a comprehensive understanding of capabilities and limitations. This section could also relate to carer expectations by identifying and providing contact details for services likely to be encountered throughout the course of the caring role. Whilst it is clearly important to include contact details of supportive organisations and resources, this would require maintenance due to organisational changes and recommendations. Previous web-based interventions have also included a referral feature to external organisations (Lobban et al., 2017; Glynn et al., 2010; Sin et al., 2019a).

Supplementary content could include suggested questions for services and a 'jargon buster' of medical or therapeutic terms. A 'jargon buster' would be particularly useful to those commencing a caring role who may have limited experience of mental health services. For instance, CBT can refer to cognitive behavioural therapy or compulsory basic training required to drive a motorcycle in the United Kingdom. Whilst the context could indicate the connotation of the acronym, if similar terms are used within the same setting this could increase confusion.

5.3.3 Web-based forums and chat features

Proposed web-based forums could include carers, carer and care recipient, and carer and professionals. Regarding web-based forums for carers, it is important to acknowledge the different needs of carers at various points of the caring role. Whilst communication with long-term carers can be valuable to new carers due to sharing experiences and knowledge exchange, one carer reported the risk of distress caused by displays of hopelessness. Based on this, forums could be separated in accordance with length of the caring role,

however integration during specific events could facilitate knowledge exchange with minimal exposure to stress. Providing an individual forum for carers could create concerns regarding quality of information shared and risk of over disclosure. One solution could be security features identifying words indicating risk (e.g. Lederman et al., 2014), however these are not infallible and would need to be monitored. Additionally, there would need to be a creation of a procedure for the identification of risk. This is outlined in more depth later in this chapter.

Rotondi et al. (2010) included a shared chatroom with individuals with schizophrenia and family members within a web-based intervention. Whilst some carers noted the usefulness of this in terms of understanding perspectives, others noted the possibility of distress. Similarly, one solution could be the creation of separate web-based forums with the ability to interact during specific points. The use of a carer and care recipient forum could suggest the benefits of an intervention for both carers and individuals with schizophrenia.

Finally, a web-based forum for carers and professionals can promote collaboration between these parties and provide personalised support. This is similar to the 'Ask the Experts' component included in previous web-based interventions (Rotondi et al., 2010; Sin et al., 2019a; 2019b), where users posted questions which were answered by healthcare professionals. However, as participants identified difficulties deriving from the relationship with healthcare professionals, this should be an optional feature and provided alongside additional web-based forums.

5.3.4 Referral feature

The research underpinning this thesis has highlighted a negative appraisal of web-based resources and information, and the preference for non-web-based resources. This could indicate the usefulness of a referral feature or service directory in enabling personal choice regarding supportive needs. Additionally, this feature could signpost carers to organisations to assist in the development of technological skills. This will be outlined in further depth later in this chapter. Previous research has included a resource directory for carers of individuals with schizophrenia or psychosis which featured web-based and non-web-based links (Lobban et al., 2017; Lobban et al., 2013; Sin et al., 2019a). Whilst the results of this web-based intervention are in press, the results of the research informing

this thesis could indicate that the inclusion of a resource directory would influence appraisal of web-based resources whilst meeting carer supportive needs.

Further considerations regarding referral include the occurrence of high scores identified through the needs-based algorithm or posts by the carers. Scores indicating moderate distress could result in carers being referred to relevant web-based content with the support of a moderator or therapeutic professional as support. However scores indicating high levels of distress or indicating a risk to themselves or the care recipient would require further support. The provision of emergency support could be difficult to achieve within a web-based format due to the distance between moderator and carer accessing the resource. Whilst contact details could be provided, it would be difficult to ensure that these services were contacted. Alternatively, this could implement an alert through which the moderator could refer emergency services or the crisis team to the carer. However, this would require carers supplying personal contact information, the provision of which was identified as a key barrier to support access by one carer.

5.3.5 Ensuring the safety of a web-based resource

Participants outlined the importance of ensuring safety for users of a web-based intervention. Whilst security of service users has been a continued consideration in providing healthcare, the occurrence of high-profile news stories has reiterated the responsibility of services towards users' safety and privacy. One example is the 2017 NHS cyber-attack where 16 health service organisations were infiltrated by ransomware; a computer virus that prevents access to a technological device until a ransom is paid (Telegraph, 2017). The occurrence of these cyber-attacks and portrayal or sensationalism within the media could impact individual perception and confidence in data protection. Subsequently, this could influence an individual's willingness to disclosure on web-based resources. Thus, Doherty et al. (2010) reported the need to reassure users of data security and promoting discretion, for instance permitting the user to indicate whether audio is played when viewing a video.

Whilst the technological aspects of web-based interventions are beyond the remit of the research underpinning this thesis, security regarding web-based resources should be a constant consideration from development to maintenance. Previous web-based interventions have utilised a collaborative working ethos between healthcare professionals and IT specialists (for example, Gleeson et al., 2014). Other authors have

highlighted the importance of including HCI specialists in the construction of web-based resources (Doherty et al., 2010).

Within their model for a web-based intervention for individuals with FEP, Lederman et al. (2014) proposed the following guidelines to ensure continued safety for intervention usage;

- Enabling users to report concerning posts or accounts
- Inclusion of emergency information
- Permitting users to conceal profiles and contributions to forums to facilitate privacy
- Use of password protection and pseudonyms to aid confidentiality
- Users were referred by health service following assessment for suitability, in this the authors advise that high-risk populations are excluded
- Automated word system to identify risk, for example 'suicide'

Whilst the above guidelines were proposed for the construction and evaluation of a web-based resource for individuals with FEP, these are also relevant for the security of an intervention designed for carers and family members.

5.4 Further tentative considerations

Having outlined the overall considerations of the CNAF, attention will turn to tentative conclusions and implications for future research. This section will begin by considering the inclusion of training components before introducing carer and care recipient contributions towards resource construction. Following this, the use of alternative mediums for information provision and the aspect of permanence with web-based resources will be presented.

5.4.1 Inclusion of training components

Two training aspects will be considered in this section; training regarding technology use and training as a supplementary factor to information components on a web-based intervention. Regarding training for technology usage, this framework is aimed at individuals with access to and who are proficient in using technological devices. Despite

this, a web-based introduction or tutorial to the intervention could be useful to facilitate usage and reduce possible frustration.

It is important to consider individuals who are unable to utilise web-based resources. The DCMS (2017) stated the intention of increasing minority access to web-based resources to minimize the digital divide and increase access to services and employment. Suggested solutions to this included overcoming causes of digital exclusion, provision of skill development and collaboration with public, private and third sector organisations. Partnership with professional organisations would be beneficial to those with access to technological devices but who lack technological literacy. Organisations are unlikely to provide technology, however they would be able to refer individuals to resources to assist use or could provide training to overcome this barrier. For example, Dow et al. (2008) provided workshops to educate older carers about technology, resulting in increased confidence and a positive impact on carer health.

Further suggested training content refers to the identification of quality resources available on the internet. Whilst the findings of the research informing this thesis have indicated the importance of providing high quality information, carers may continue to search for external web-based resources. Therefore, training regarding assessing the quality of content could be valuable to carers. The training could include content relating to reporting harmful sources found online. Further considerations regarding fundamental technological and quality assessment skill development could be considerations for future research.

The inclusion of a training section could also refer to a supplementary component to web-based information, providing information in an interactive format. For instance, whilst content could focus on mindfulness to improve carer health, the training section could provide videos demonstrating breathing techniques and further explain this process. Additionally, the training section could provide mental health training regarding recommended responses likely to be encountered with individuals with schizophrenia. Although the debate relating to training family members similarly to healthcare professionals has been considered previously in this chapter, it will be briefly outlined here. Family members currently provide care for their ill relative without official training that could facilitate completing this role and promote health. Receipt of training could also increase collaborations with healthcare professionals regarding treatment. However, this could raise concerns regarding accountability and responsibility towards the care recipient and providing care. Additional concerns relate to carer health; for instance,

increasing responsibility on individuals who may already be experiencing extreme distress and are therefore aggravating this condition.

5.4.2 Carer and care recipient contributions towards resource development

This section will begin by considering carer and care recipient contribution to the construction and evaluation of a web-based intervention before focusing on continued resource development. Participants indicated the usefulness of collaborating with carers and professionals in developing a web-based intervention. A key example was incorporating personal stories or written articles contributed by carers or individuals with schizophrenia. Regarding personal stories, one professional argued that these could increase hope and reduce isolation experienced by carers. Inclusion of written articles could provide an alternative perspective to illustrate information content whilst providing a carer-focused viewpoint supported by previous literature (Lloyd and Carson, 2005). Further examples of collaboration with carers could include suggestions for intervention improvement, such as topics for inclusion or better presentation or usability. Although not directly referred to by participants, these suggestions arise from participants identifying these as barriers towards intervention adherence.

An additional method for increasing carer contribution to a web-based resource includes establishing a volunteer system to assist moderation of forums. Considered within the supportive accountability model, Lederman et al. (2014) outlined users' ability to flag concerning posts or potential misuse of resources. Lederman et al. argued that undertaking this task encourages user responsibility of posts. Whilst this could be beneficial in ensuring carer collaboration and reducing financial pressures, this could place responsibility on carers who may be experiencing a stressful situation. Therefore, there would be a requirement to assess carer suitability and capability to complete a voluntary moderation role to reduce possible stress.

5.4.3 Live events: The use of various technological mediums for information sharing

The evolution of technology has provided increased ability to distribute information via an interactive format. For instance, the use of video, activities, podcasts or the ability to

live stream events occurring at one location to alternative sites (for example, see Haley et al., 2011). Live web-based events can provide information via an interactive format as opposed to written text. For example, webinars can feature training events focusing on responding to individuals with schizophrenia or psychosis who are experiencing an auditory hallucination. Not only can this be beneficial to carers with similar experiences, the availability of a concurrent chat component can facilitate a person-centred approach by enabling questions. An additional example of a live event is a question-and-answer session with a healthcare professional. For instance, carers submit questions in advance of the session which are answered by a professional during the live stream. The ability for advance contributions by carers can allow moderation and prevent similar questions. Attendance at live events could increase interaction between carers and professionals whilst also providing an understanding of situations and abilities. Presently, only one web-based intervention included a form of live events, as Glynn et al. (2010) provided a regular bi-weekly live chat discussion regarding medication and treatment.

Previous research into web-based interventions have incorporated an interactive component to information sharing, for instance videos featuring authentic carer stories portrayed by actors or content relayed by healthcare professionals (Lobban et al., 2017; Sin et al., 2019a). The National Literacy Trust (no date) reports that 16% of UK adults portray literacy difficulties; an impediment indicating barriers to comprehending written text. Thus, the provision of information via alternative mediums could increase accessibility and understanding to these populations. Chan et al. (2016) investigated the impact of a web-based intervention including downloadable YouTube videos. These authors reported an increase in carer subjective knowledge following usage, indicating the acceptability and usefulness of information provided in different mediums.

5.4.4 Creating permanence and keeping updated

Participants appeared to perceive web-based resources as a safety net that could be accessed when required for reassurance and knowledge. Although participants referred to previous web-based resources that were no longer available, the internet was still associated with permanence. Therefore whilst the creation of a web-based resource could achieve this mechanism, this could be further enhanced by providing components such as an archive and a storage locker.

An archive could provide access to previously-posted questions or live events, therefore increasing access to those unable to view content when originally posted. This could further provide access to individuals encountering a new situation and therefore developing a need for support. The storage locker could allow carers to save useful information and links for reference when needed (for example, see Lobban et al., 2017). The availability of information could be invaluable for carers encountering a new situation, particularly if transferable across devices and available offline.

A 'keeping updated' section of a web-based intervention could highlight changes and updates to the resource, policy or law. This section could be useful in informing long-term carers of changes and newly-available support. With reference to previous literature, only one web-based intervention included a keeping updated section which was used to promote awareness of news and events (Rotondi et al., 2005; 2010). However, Rotondi et al. (2005) reported that family members would value updated news on medications and alternative treatments for schizophrenia. This could indicate the usefulness of a research section to update carers and facilitate knowledge exchange. Finally, an additional example of ensuring carers continue to remain informed of new developments could include a mailing list. This would provide updates regarding the web-based resource and content relating to schizophrenia or the caring role. A further advantage to this approach is that the regular communication or reminders provided to carers could promote adherence to the web-based intervention.

5.5 Chapter summary

The purpose of this chapter was to provide further discussion and present the CNAF which can guide the construction and evaluation of web-based interventions. This chapter began by presenting the key elements of the CNAF for a web-based intervention, which was aligned to the findings identified from the research informing this thesis. Three fundamental prerequisites, relating to accessibility, landscape of carer support, and communication components, were outlined. Two fundamental elements consisted of the acknowledgement of expertise via experience and empowerment through knowledge. The CNAF suggests that these five elements contribute to carer and care recipient wellbeing and QoL.

Following this, ten proposed components of a web-based intervention were outlined, with five of these being considered as tentative further suggestions. Intervention components included a needs-based algorithm to identify carer needs and provide direction towards relevant support. Examples of tentative considerations included incorporating training components (for instance, caring role management) and the use of live events to encourage adherence with the web-based intervention. Each section was considered in relation to previous research.

The following chapter will discuss the quality of the research informing this thesis, focusing on validity in both qualitative and quantitative methodologies.

Chapter 6. Determining the quality of the research underlying this thesis

6.1 Chapter overview

This penultimate chapter will consider the quality of the research informing this thesis in accordance to undertaking a mixed method and a critical realist approach. In doing so this chapter will consider quality assessments for quantitative and qualitative research before turning attention to mixed methodological approaches and critical realism. Following this, researcher reflexivity will be considered in terms of previous experience and development of knowledge completing the research underpinning this thesis.

6.2 Determining the quality of the research informing this thesis

Zachariadis et al. (2013) define validity as:

> *"the level of quality and rigor of research and can have a significant impact on the quality of inferences that are generated from a study" (p4).*

However, the amalgamation of qualitative and quantitative approaches has been noted to generate issues regarding validity (Creswell and Plano Clark, 2011). Therefore, Creswell and Plano Clark provide the following guidelines to the evaluation of mixed method research;

- The confirmation of qualitative and quantitative data collection and integration of data to deliver a deeper understanding of the focus of study
- Use of a mixed methods research design
- Identification of philosophical theoretical underpinning
- The use of terms consistent with a mixed method approach.
- Rigour in data collection and analysis

In relation to the above guidelines, chapter three has presented the mixed method design and outlined qualitative and quantitative methods of data collection. Quantitative data was collected by use of health questionnaires and demographic information, while in contrast qualitative data consisted of individual interviews with carers and professionals.

Weekly diaries of web-based support usage included both quantitative and qualitative components, measuring the amount of access and qualitative comments regarding views of resources. Findings were integrated to provide an overview of the focus of interest and used for the development of a framework for the construction and evaluation of web-based interventions. Regarding the identification of philosophical underpinning, much time has been placed on the introduction and justification of a critical realist approach underpinning the research informing this thesis, discussed in relation to quality later within this section. This was further considered within the presentation of generative mechanisms and contexts in chapter four.

Creswell and Plano Clark (2011) advocate for the use of terms consistent with a mixed method approach in research evaluation. The authors suggest that this indicates an effort to follow mixed methods procedure and awareness of relevant literature. This criterion entails inclusion of mixed methods terminology within sections such as method discussion and rationale for use of this approach. Chapter three introduced mixed methods as the approach applied within the research informing this thesis, specifying the design as classified by Creswell and Plano Clark. The chapter further considered aspects such as triangulation to include multiple perspectives and as a form of quality assessment.

Concerning rigour in data collection and analysis, it is useful at this point to acknowledge the difference in evaluating quality of quantitative and qualitative research. The research informing this thesis was a mixed methods design incorporating qualitative and quantitative approaches, though the latter is summative and descriptive. Therefore, statistical conclusion validity (as outlined in Table 6.1) was not achievable in the research informing this thesis due to the limited sample size. The quantitative element provides views about the phenomenon from one perspective, however given the limitations of sample size a strength of this research is richness obtained from qualitative data. The resulting theoretical framework is aligned to the qualitative and QCA data analysis. Despite the summative nature, the quantitative data is complementary to the qualitative, further adding weight to the quality of the findings.

The key considerations of validity in quantitative research, as outlined by Creswell and Plano Clark (2011) and Zachariadis et al. (2013), are outlined in table 6.1. The key considerations towards assessing the quality of quantitative and qualitative research methodologies are outlined below.

Table 6.1 An overview of validity classifications in quantitative research

Type of validity	Subsection	Definition
Design validity	Internal validity	The capacity to verify cause and effect concerning variables of interest and control of bias
	External validity	The ability to generalise results to ensure applicability to wider population
Measurement validity	Reliability	The consistency of scores over different time points, assessed by consideration of internal validity of questionnaire scores.
	Construct validity	Variables or questionnaires accurately measure the phenomenon of interest.
Inferential validity	Statistical conclusion validity	Appositeness of statistical analysis

As can be seen from the above table, internal validity refers to the identification of the cause and effect of studied variables. However, critical realism designates this as a black box and provides a description of events when the focus should be placed on generative explanations (Bhaskar, 1975; 1998; Pawson and Tilley, 1997). Therefore, critical realism proposes the importance of identifying generative mechanisms and the contexts in which these occur as an explanation for observed effects, i.e. empirical level of a stratified reality. Zachariadis et al. (2013) considered internal validity in relation to a critical realist perspective, proposing that internal validity should refer to the likelihood of observed effects being indicators of identified generative mechanisms and contexts.

The identified generative mechanisms and the contexts in which they act were identified through individual interviews with carers and professionals and were attributed towards improved carer emotional health. Some mechanisms demonstrate a clear association to an empirical effect on health. For instance, carer level of understanding and technological literacy includes the ability to and confidence in utilising web-based resources. The inability to use technology would impede access and therefore fail to impact on carer health. While other mechanisms could have an impact on carer health, they may also require further examination to fully determine this. One such example is technological remoteness; whilst participants highlighted the importance of this mechanism in engagement with web-based resources and reduction in isolation, future research could confirm an impact on carer health.

External validity refers to the ability to generalise results to the wider population, for instance whether the results of the research informing this thesis is applicable to wider

carer sample. In relation to critical realism, external validity refers to the probability that observable events in other similar contexts are the results of the identified generative mechanisms (Zachariadis et al., 2013).

The proposed generative mechanisms were identified as causal factors towards web-based support use and impact on carer wellbeing or QoL. Some of the proposed generative mechanisms have clear transference to other situations for individuals providing care for relatives with a different diagnosis or general access of web-based health interventions. For instance, participants highlighted the impact of age on intervention access and technological literacy, and previous research has identified age as a significant barrier to web-based support access (Blackburn et al., 2004). Other generative mechanisms such as carer and care recipient needs are generalisable to carers who are providing care for individuals with different diagnoses. However, this may not be as applicable to members of the general population.

Regarding reliability and construct validity, chapter three has outlined the health questionnaires utilised in the research informing this thesis. Previous research has reported strong validity and reliability scores of these measures, indicating appropriateness for use within the research informing this thesis (Stewart-Brown et al., 2009; Tennant et al., 2007; Brand, Barry and Gallagher, 2016; Hallam and Morris, 2014).

Having considered the criteria for quality assessment for quantitative research, attention turns to consideration of qualitative research. Guba (1981) proposed four principles to determine the reliability of qualitative data and results: credibility, transferability, dependability, and confirmability. Credibility in quality assessment has been defined as determining the authenticity of findings, and therefore has been linked to internal validity (Guba and Lincoln, 1994; Miles and Huberman, 1994). Miles and Huberman proposed a list of queries to assess the above principles, suggesting that credibility of research could be indicated with, for instance, in-depth descriptions and the amalgamation of results through triangulation. Referring to credibility within a critical realist perspective, Zachariadis et al. (2013) stated that this includes the generative mechanisms and associated contexts.

The research informing this thesis has portrayed five key themes relating to carer web-based support use and the impact of this on carer wellbeing and QoL. These themes were described and presented with quotes from individual interviews and weekly diary entries. Concerning triangulation of multiple datasets, chapter four integrated qualitative

comments from weekly diaries and individual interviews. The identification of generative mechanisms and contexts were outlined before being aligned to the theoretical framework and considered in more depth in chapter five.

Transferability has been defined as the generalisation of qualitative research and therefore has been linked to external validity (Denzin and Lincoln, 1994). Traditionally, the generalisation from qualitative research has been considered difficult as results are reflective of location, time and feature small samples. Williams (2000) argued that despite qualitative researchers' reluctance to acknowledge this existence, generalisation from qualitative research is inevitable and occurs frequently. Williams further proposed the application of moderatum generalisation; i.e. qualitative findings being considered as "instances of a broader recognisable set of features" (p215) generalizable across cultures. In relation to the research informing this thesis, the findings and resultant CNAF could be applicable to carers, particularly those caring for individuals with a mental illness. The generalisation of the findings informing this thesis are outlined in the following chapter, which discusses the implication of the proposed theoretical framework on practice and applicability to alternative populations.

Dependability has been compared to reliability within quantitative research (Denzin and Lincoln, 1994). For instance, dependability relates to how consistent research findings remain over time and with the use of alternative methods (Miles and Huberman, 1994). Regarding queries to determine dependability, Miles and Huberman's proposals include the clarity of research questions and congruence of methods. In relation to a critical realist approach, Zachariadis et al. (2013) suggested that this was "an essential part of the retroductive process and identification of contingent factors" (p6). Concerning the above criteria to assess quality in qualitative research, this thesis has provided the research questions and outlined methods taken to investigate these. Chapter four also outlined the process of retroduction undertaken in the identification of causal mechanisms and contexts.

Finally, confirmability relates to acknowledgement of the influence of researcher bias on interpretation of results (Miles and Huberman, 1994). Proposals to consider this quality aspect include explicit description of methods (including an audit trail) and researcher awareness of personal bias and assumptions that may have influenced the study. Regarding critical realism, confirmability refers to information about generative mechanisms that result in observable effects, often obtained through qualitative data analysis (Zachariadis et al., 2013).

Regarding confirmability, chapter three has presented a detailed outline of the methods applied in the research informing this thesis. Data collection documentation is included in appendix three for further consideration. To address and minimise potential personal bias, reflective sections have been included in the introductory chapter and the development of the conceptual framework informing the research informing this thesis. Further consideration towards research reflexivity is provided within the following section.

The research informing this thesis has been explicitly reported here in terms of conceptual framework and underlying philosophical and theoretical assumptions, methodology and research design in practice. The data which informed the analysis has also been illustratively laid out in order to represent a clear audit trail for the analysis and resultant CNAF.

6.3 Considering researcher reflexivity and positioning within the research process

Chapter three has considered the differences between qualitative and quantitative approaches, particularly the situation of the researcher within the conduction of research. Quantitative research advocates the importance of researcher objectivity while qualitative research accepts the researcher position (Mertens, 2010; Winter, 2000). As a result, qualitative research encourages the process of researcher reflexivity as a form of quality assessment. Bryman (2016) defines reflexivity as a "reflection of a researcher's location in time and social space" (p388). Bryman goes on to state that reflexivity is twofold;

> *'... Social researchers should be reflective about the implications of their methods, values, biases, and decisions for the knowledge of the social world they generate. Relatedly, reflexivity entails a sensitivity to the researcher's cultural, political, and social context.' (p388).*

In the interests of reflexivity, I completed a research audit trail/diary indicating key decisions and theoretical development throughout the course of the research that informs this thesis. An example of theoretical development in the research diary is included within appendix five. The conceptual framework presented in chapter three incorporates reflexivity and the relationship of this to the topic of interest and decisions made throughout the research process.

My interest in psychology and mental illness originally stemmed from a close family member being diagnosed with an SMI and from family members working in the healthcare service. Although I was young and unable to fulfil a caring role at this time, this resulted in an interest in mental health which later led to my application to complete an undergraduate psychology degree at Northumbria University. During my degree, I developed a strong interest in research methodology and analysis, resulting in completion of a master's degree in research. Whilst this predominately focused on quantitative research, I also developed an interest in qualitative research and the usefulness of combining both approaches.

My interest in carer web-based interventions stemmed from the advertisement of a PhD studentship and resulting literature search. Therefore, to some extent, the research project was allocated. However subsequently through the process of research design, execution, analysis and writing, I have taken control within these parameters.

The PhD journey has been considered as a research apprenticeship in that this provides the opportunity for the development of skills in the designing and implementation of a research project. Onwugezbie and Leech (2005) noted that the psychology discipline prioritises quantitative research methodology. My prior experience reflects this perspective and, upon beginning the research informing this thesis, my knowledge was largely centred on psychological quantitative research. Therefore, I had limited understanding regarding ontology and epistemology and the value of conceptual frameworks in the research process. I have appreciated the opportunity to develop an in-depth understanding of research philosophy and the influence of this on research design. I have also further developed my initial research skills, and gained confidence utilising these skills, especially in terms of participant recruitment. Upon reflection of the research process, I feel it would have been valuable to engage with the conceptual framework earlier in the research process, particularly in relation to critical realism and complexity theory. The value of a conceptual framework as a ballast at all stages of the research process has been outlined in chapter three. Earlier engagement could have increased understanding regarding these ontological perspectives and assisted in decisions in the research process.

My relative's diagnosis of an SMI and facilitating caring tasks for other family members has provided me with a basic insight into carer needs. Completing this thesis has further highlighted to me the impact of the caring role on the carer's health and the experiences of my family members in particular. The research informing this thesis had the further

advantage of developing a deeper understanding of carers' supportive needs and an opportunity to improve carer health.

Further considerations include the implications of my age on participants, and I was conscious that this could be associated with limited life experience and proficiency with technology. The result of this could influence rapport with older participants and information shared within individual interviews. My familiarity with technology, and that of my social circle, led to an assumption that carers would have access to this, which again could have influenced rapport with participants. I was also aware of my research background and limited therapeutic experience in engaging with this research project. Therefore, I approached this project from a research perspective and was conscious of my inability to advise relating to the caring role experiences. It is possible that my lack of therapeutic experience may have impacted on rapport with participants.

6.4 Chapter summary

This chapter has considered the quality of the research informing this thesis. By doing so, this chapter has considered quality criteria for qualitative and quantitative research methods in consideration with a critical realist perspective. Following this, this chapter compared the quality criteria in association with the research informing this thesis.

The issue of reflexivity in the research process was addressed and included an outline of the researcher's positioning within the research underpinning this thesis. The researcher's positioning considered the impact of the researcher's prior experience with a relative diagnosed with an SMI and quantitative background. This was then discussed to inform the researcher's development of knowledge and experience throughout the research journey.

Chapter 7. Conclusion: Final considerations for practice and suggestions for further research

The final chapter of this thesis will begin by providing an overview of the previous chapters. Focus turns to considerations of the implications of the research informing this thesis and the proposed impact of the CNAF on healthcare practice. This impact is illustrated at micro, meso and macro levels. Following this, this chapter considers proposals for future research before concluding this thesis.

This thesis has drawn upon a research study focusing on a framework for the construction and evaluation of a web-based intervention for carers. In doing so, the research underpinning this thesis has considered the impact of web-based resource use. This research also incorporated carer and professional views regarding web-based resources and the construction of an intervention. It is useful at this stage to revisit the research questions:

1. What typologies of web-based support are available for carers of people with an SMI?
2. What is the perceived impact/utility of web-based support upon carer well-being and quality of life?
3. What are carers' views and perceptions of the factors which constitute effective web-based support for them?

The literature chapter identified three key themes of literature; schizophrenia and psychosis, carers of individuals with schizophrenia and psychosis, and web-based support to promote healthcare. The theme schizophrenia and psychosis considered aetiology including the theoretical impact of family members on illness development and progression. Following this, it discussed the diagnosis of mental illness and associated stigma experienced by individuals and their family members. This theme also considered the perceived risk associated with schizophrenia and psychosis, reporting on the impact of moral panic on appraisal of mental illness. Concerning carers, this theme discussed the development of expertise via experience and the promotion of a collaborative approach to healthcare. The impact on the caring role on carer health and available support was

also considered. The final theme considered the use of web-based support in healthcare and previous research focusing on carer support provision. Finally, concerns regarding web-based support use in terms of privacy, technological literacy and the impact on services were addressed.

The research design and approach chapter presented the conceptual framework underpinning the research informing this thesis. In doing so, this outlined critical realism as the ontological approach, informed by complexity theory, informing this research and specified the identification of generative mechanisms indicative of the observable effect of interventions. This chapter presented a mixed methodological approach; carers were invited to complete health questionnaires, keep a weekly diary measuring web-based support use, and take part in individual interviews regarding available web-based forums and the construction of an intervention. Professionals who regularly worked with carers of an individual with an SMI were also interviewed. Thematic analysis and QCA were outlined as analysis processes and aligned to the critical realist approach and complexity theory.

Chapter four presented findings and initial discussion. This chapter began by reporting quantitative descriptive data analysis of weekly diaries of web-based resource use and impact of use on carer health. Two QCA-identified causal factors related to weekly web-based support use and influence on carer health were identified using week three as the highest point of web-based support use. Please note that these initial results are summative and descriptive due to the small sample size. Thematic analysis of individual interviews and weekly diaries resulted in five themes. Themes identified the importance of information on carer empowerment, the rise of expertise via experience, the value of communication, available support for carers and appraisal of web-based resources, and a person-centred approach to support seeking. In accordance to the critical realist perspective, generative mechanisms and the contexts in which these operate were identified from individual interviews.

Finally, chapter five presented the CNAF theoretical framework aligned to the findings of the research informing this thesis. Based on these elements, recommendations have been made and are summarised as follows;

- The inclusion of a needs-based algorithm.

- Information components providing content regarding schizophrenia, practical information for carers, and advice regarding professionals and supportive resources.
- Web-based forums and chat features allowing communication with others with similar experiences. Providing forums allowing interaction with professionals and individuals with schizophrenia could increase understanding of experiences.
- A referral feature directing users to alternative resources to promote personal choice and reduce negative appraisals of web-based resources.
- Consideration of security.

This theoretical framework also tentatively suggested the following components;

- Training components relating to technology use or the caring role and overcoming situations encountered.
- The inclusion of carer and care recipient contributions, for instance personal stories and written articles.
- Live events and use of different technological mediums to present information.
- The enhancement of permanence in web-based resources.
- A component to encourage up-to-date information regarding schizophrenia and available support for carers.

The quality of the research informing this thesis was considered in chapter six. This began by considering the quality assessments within quantitative and qualitative research, such as triangulation and member checking, before turning attention to mixed methods research and a critical realist approach. This chapter also considered issues of reflexivity and the researcher's positioning within the research process.

The proposed CNAF facilitates the construction of a web-based intervention. This framework can also guide evaluation of present web-based interventions by considering the impact of this resource on carer wellbeing and QoL. The research informing this thesis has also provided a greater understanding regarding generative mechanisms informing or prohibiting the utilisation of web-based resources, for instance the negative appraisal and level of humanness of web-based resources. A deeper understanding of these generative mechanisms and the contexts in which they operate can facilitate the implementation and recommendation of web-based resources to promote accessibility and effectiveness.

At the micro level, the development of a web-based intervention could provide carers with easy access to a supportive resource at any time. The framework presented within this thesis suggests that usage of the web-based intervention will result in increased empowerment leading to a promotion of carer emotional health. For instance, participating within a web-based forum could reduce feelings of isolation and increase understanding of the care recipient's experience. The proposed framework also considers generative mechanisms relating to the access and repudiation of web-based resource access, therefore identifying potential barriers to be addressed in the offering of web-based support.

At a meso level, the research informing this thesis has highlighted tensions between organisations and web-based resources. Participants demonstrated a negative appraisal of web-based resources due to concerns of the subsequent impact on organisations and services. If a professional displays a negative attitude whilst referring to support, this could influence carer engagement, especially when considering carer appraisal of web-based resources. This indicates the importance of collaborating with organisations to influence engagement. This could further indicate the value of considering the impact of web-based resources on an organisational level, for instance the sustainability of non-web-based support due to the assumption of cost effectiveness of web-based resources at the macro level. However, acceptance of web-based resources could relate to implementation in organisations, indicating the importance of exploring this within future research (May and Finch, 2009; Murray et al., 2010).

Finally, regarding a macro level of implications, this thesis complements recent proposals regarding carer web-based support (DoHSC, 2018a; 2018b) and the NHS long-term plan (NHS, 2019). These recent policies indicate the continued transition into the use of digital or web-based resources in healthcare promotion, otherwise referred to as evolution.

A clear recommendation for future research is the construction and evaluation of a web-based intervention based on the proposed theoretical framework. Whilst generalisability within qualitative research has been discussed within this thesis (e.g. William, 2000), due to the small sample size it could be useful to discuss the proposed theoretical framework to ensure generalisability. In doing so, this constitutes what Doherty et al. (2010) refer to as a transition to the review stage of mental health-based technology development. These authors go on to highlight the value of including mental health and human-computer-interaction (HCI) professional input towards resource construction. Whilst the research informing this thesis incorporates the views of voluntary and healthcare professionals, the

integration of an HCI perspective could influence adherence and usability of a web-based intervention.

Much time has been given in this thesis to outline and justify the use of a critical realist and complexity theory-informed approach. Whilst an RCT can be considered to be gold standard in assessing the impact of an intervention, this has been critiqued for providing a black box approach or failing to consider the complexity relating to a perceived effect (Bhaskar, 1975; Pawson and Tilley, 1997; Byrne, 2013). Therefore, future research should assess the impact of a web-based intervention on carer health whilst testing the proposed generative mechanisms or causal conditions to provide an explanation.

Although this framework focused on the construction and evaluation of a web-based intervention for adult carers of individuals with schizophrenia or psychosis, many principles could be applicable to young carers. The impact of the caring role on young carers was briefly considered earlier in this thesis (for instance, Vizard et al., 2018; Somers, 2007). Although this group are likely to have own consideration of needs, the assumption of the relationship between age and technology use could indicate consideration for future research (Ali et al., 2013). Alternatively, the proposed theoretical framework could be pertinent to carers of individuals with other mental health diagnoses, for instance bipolar disorder or personality disorders. Future research could explore the applicability and acceptability of a web-based intervention for other carers.

Further suggestions for future research could investigate key aspects raised in individual interviews, for instance the relationship between carer and care recipient health, training of carers, and use of a mobile phone app. The relationship between carer and care recipient health has been explored within previous literature, for example that relating to EE (Kuipers et al., 2005; Koutra et al., 2015). The proposed needs-aligned framework for the construction and evaluation of a web-based intervention propositioned the impact of empowerment on carer health and, subsequently, care recipient health. Therefore, research could also investigate the impact on care recipient health following carer use of the web-based intervention.

Participants suggested training carers similarly to healthcare professionals to increase carer empowerment and facilitate management of the caring role. However, considerations towards this training include risk and the suitability in providing this to carers. Previous literature and the findings of the research underpinning this thesis has highlighted the impact of the caring role on carer health and a needs-based approach to

support seeking. The provision of mental health training could further intensify carer distress and perceptions of responsibility towards the care recipient. Additionally, carers have reported different perceptions of risk arising from personal experiences in the caring role, as opposed to those associated with objectivity (Heyman, 1998). However, carers are providing care for their relative outside professional contact, often with limited prior experience of mental health. Therefore, the provision of mental health training could be beneficial for carer empowerment.

The findings of the research informing this thesis also tentatively propose the use of alternative technological support provision, such as smartphones. Participants were positive about the use of web-based apps to provide information and support to carers due to increased accessibility and privacy. To the author's knowledge, there has been no prior research into carer health-based mobile phone apps, indicating the scope for future considerations. Alternatively, this could be an additional feature on a web-based intervention, providing a multiplatform source of support.

To conclude, carers of individuals with an SMI provide a valuable role caring for their relative. However this can negatively impact on their health. Previous research has reported that carers have reduced wellbeing and QoL, and increased isolation and distress. The relationship between carer and care recipient health indicates that improving the health of the former can improve the latter. Therefore, it is important to improve carer health and increase access to support. As carers have reported barriers to non-web-based support, consequently the internet could provide valuable access to information when needed.

The research informing this thesis has summarised and described available web-based resources and the impact of these on carer health. QCA has advanced the understanding of the impact of web-based resources by identifying relevant causal conditions on carer wellbeing and QoL. Thematic analysis of qualitative interviews identified five key themes relating to web-based resource use. Generative mechanisms and contexts were identified through QCA and thematic analysis to further enhance understanding.

This thesis has also presented a needs-aligned framework for a carer web-based intervention. Aligned to the findings from the QCA and thematic analysis, this framework proposes fundamental prerequisites of empowerment via knowledge which, in turn, impacts wellbeing and QoL. The proposed framework provides guidelines for the construction and evaluation of a web-based intervention.

On a micro level, the construction of a web-based resource would have clear implications on carer health and, in turn, influence the health of the care recipient. The findings have also indicated negative appraisals towards web-based resources, particularly in the meso level.

Whilst the present framework is focused on carers of individuals with an SMI, this could be applicable to other carers, such as young carers. The identification of generative mechanisms and the context in which they operate provide further understanding regarding adherence to and the impact of web-based interventions in a healthcare setting.

It is important to promote carer health, not only to increase their health but the health of the care recipient. Whilst web-based resources provide a useful medium for support, it is important to consider the implications of negative appraisals and personal choice in fulfilling supportive needs.

Appendices

Appendix 1: Ethical approval documentation, information briefs and consent forms.

Appendix 2: Participant recruitment documents

Appendix 3: Carer and professional questionnaire, weekly diary, carer and professional interview topic guides

Appendix 4 : QCA analysis

Appendix 5: Overview of analysis and reflective diary.

Appendix 1: Ethical approval documentation, information brief and consent forms.

Professor Dianne Ford, CBE FRCN
Executive Dean

This matter is being dealt with by:

Professor Jennifer Watling
Associate Dean
Faculty of Health & Life Sciences
Northumberland Building
Newcastle upon Tyne
NE1 8ST

Date 26/10/2016

Dear Amy Johnson

Faculty of Health and Life Sciences Research Ethics Review Panel

Title: REACHING OUT TO CARERS OF FRIENDS AND FAMILY WITH PSYCHOSIS: A MODEL FOR AN ONLINE INTERVENTION TO IMPROVE CARER WELLBEING AND QUALITY OF LIFE.

Following independent peer review of the above proposal and your effective changes in response to feedback, I am pleased to inform you that University approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent Disclosure & Barring Service (DBS) and occupational health clearance as needed if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available from the following web link:

https://www.northumbria.ac.uk/research/ethics-and-governance/

All researchers must also notify this office of the following:

- Commencement of the study;
- Actual completion date of the study;
- Any significant changes to the study design;
- Any incidents which have an adverse effect on participants, researchers or study outcomes;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely,

Maria Martinez

Maria-Ines Martinez

Member of the Faculty Research Ethics Review Panel

Vice-Chancellor and Chief Executive

Professor Andrew Wathey

Northumbria University is the trading name of the University of Northumbria at Newcastle

Project Amendment Form

Project Title: Reaching out to carers of friends and family with psychosis: A model for an online intervention to improve carer wellbeing and quality of life.	**Date original ethical approval received**: 26/10/2016
Principal Investigator: Amy Johnson	Project ref:
Date: 07/11/16	

Description of Amendment/Change:

1. I have included the PowerPoint presentations and Information-Sharing seminar booklet to be reviewed for ethical amendments. The PowerPoint presentation includes information regarding evidence-based, evidence-informed and anecdotal online support for informal carers of people with schizophrenia and psychosis. This also includes information about assessing quality of the online resources (please note, it may be better to view this as a presentation as this is very visual and includes animations). The Information-Sharing Booklet also contains the same information, but also has a jargon buster page and spaces for notes following activities. There will be someone assisting me with the information sharing seminar. Please note that all images used within this booklet originate from Word ClipArt. I would like to hold multiple information-sharing seminars at local carer groups to allow the opportunity for all carers to take part.
2. I would like those who attend the information-sharing seminar to fill out the demographic form (this is the same as the one attached to the Experimental Booklet).
3. With regards to contacting participants for the focus groups/individual interviews, I would like to offer the choice to contact them via phone or skype. This will still be recorded and transcribed as will the faceto-face interviews and focus groups.
4. I have included the outline for a weekly diary survey (available through Survey Monkey) for participants which will measure online usage.
5. I have also included a baseline information form for professionals who are working in the care group and have updated previous approved forms with a participant number box.
6. I would also like to email participants the information regarding the seminar and experimental booklet prior to the session.

7. I would also like to allow participants the opportunity to take the experimental booklet away and to complete at a later date, I would include self-addressed envelopes (to my base at the university) and stamps.
8. I have included a question on the consent form asking if the carers would like to be contacted if they receive a high score on the experimental questionnaires.

Reasons for Amendment/Change:

1. When I was initially applying for ethical approval, I was in the final stages of a scoping review which provided the content for the Information-Sharing Booklet and PowerPoint. This is an extension of my previous ethics application.
2. This is to provide more information about attendees for assessing the seminar and write up in thesis
3. By contacting participants via phone and skype, this will allow more freedom around their caring duties and less of an inconvenience to travel to a location.
4. This will provide more information about online usage, presenting a wider picture of the topic at hand, as recommended by Triangulation research (Yin, 2001).
5. I want to include this form to get more demographic information from the professionals (e.g. age) for description purposes within my thesis.
6. This is to allow participants to access the materials in a format they prefer, e.g. many people prefer to use an iPad or computer tablet.
7. This is to allow increase access to the study and to allow those who are unsure to review and consider this with more time.
8. The concern over contacting participants who had received a high score was brought up within my original ethics application, although I did provide an alternative answer, I believe this may be a more suitable course of action following discussion with my supervisor. There is a possibility that carers who attend these sessions are also service users, if this is the case than it would be likely that they would receive high scores on these questionnaires but are also seeking treatment. If this occurs, I will not exclude them from the study as I am looking into their carer role and will not be seeking any information regarding other roles.

Anticipated Implications:

I do not think there will be any implications for participants, these changes are to facilitate access to the study and to provide information regarding online additional support. The addition of the checklist for the professionals may require a small amount of extra time, however I do not think that there will be any other implications regarding this.

TO BE COMPLETED BY THE ETHICS COORDINATOR

Acceptance/Rejection	Signature:  Maria-Ines Martinez Social work ethics coordinator for Staff and PGR in the Department of Social work, Education & Community Wellbeing.
Date:16/01/2017	

Follow-up action passed to:
Reason for Rejection:

Principal Investigator	**Amy Johnson**
Project Title	**Reaching out to carers of friends and family with Severe Mental Illness: A model for an online intervention to improve carer wellbeing and quality of life.**
Project Code (where applicable)	
Date of original ethical approval	**26/10/2016**
Date of amendment request	**28/03/2017**

Description of Amendment:

Previous approach

I am currently holding information sharing seminars at North East organisations and inviting carers of someone with schizophrenia or psychosis to attend these. Those who do attend are invited to take part in a study measuring online usage and views about online support.

If participants are carers, family or friends of someone with schizophrenia or psychosis, they are asked to complete a questionnaire booklet before using online support (as they would normally do so for up to 6 weeks). They are then invited to attend an interview or focus group to talk about online support (or if they do not use this, reasons why) and what they would like to see in an online intervention. They are also asked to complete the questionnaire booklet again. If participants are professionals (i.e. they work along carers at a local carer group), they are asked to complete a baseline measure before being invited to an interview about online support.

Amendment

1. Widen inclusion criteria from carers of people with schizophrenia or psychosis to include carers of people with severe mental illness.

I would like to expand my recruitment criteria to include carers of people with severe mental illness (SMI). SMI has been difficult to define with the original definition being considered inclusive whilst recent understanding (largely focusing on the impairing nature of mental illness) appears to be more exclusive (Insel, 2013). Previous research into this appears to have followed the inclusive nature with much of this tending to focus on schizophrenia, psychosis and bipolar disorder (see Sintayehu, Mulat, Yohannis, Adera, & Fekade, 2015; Yesufu-Udechuku et al., 2015).

Similarly, this study will aim to recruit carers of people with schizophrenia, psychosis, bipolar disorder, severe depression, and personality disorders. This will serve to increase access to participants and, to my knowledge, there has not been an online intervention for carers of people with SMI. Previous research into this has tended to focus on family members or carers of specific disorders such as schizophrenia (see Glynn, Randolph, Garrick & Lui, 2010; Rotondi et al., 2010; Sin. Henderson, Pinfold & Normal, 2013) or bipolar disorder (Berk et al., 2013; Proudfoot et al., 2007). With regards to this, I have also included a question on the Carer Information Form asking for the diagnosis of the care recipient.

2. Widen inclusion criteria to include health professionals from NHS Trusts who work with people with severe mental illness and their families.

I would also like to interview a wider range of professionals who work alongside carers of people with severe mental illness about online support (such as those who work in
NHS Trusts). I will not access patient or carer identifiable data for this study. I have contacted the NHS Research and Development team for more information regarding this and have received the relevant form, which I have included in this application.

3. Drop the information sharing seminars as a means of recruitment and include social media and other online methods.

Carers, family and friends of someone with severe mental illness.

I would like to drop the information sharing seminars (however I will honour those which I already have booked) and contact carers of people with SMI through carer groups to invite them to take part in my project. To do this, I would like to ask carer groups (some of whom I have already contacted about the information sharing seminars) to disseminate study information (e.g. participant brief) to their members and a message stating that those who are interested should contact me via my university email address. One of these carer groups has offered to include a call out within their newsletter. If these carer groups are based in the North East, I will offer to meet at the university (City or Coach Lane Campus) or at their local carer group. This will follow the same process as before (i.e. completing a questionnaire booklet, completing an online diary and attending an interview), I would also like to give them a guide to using the survey (this has been included within this amendment). If carers are unable to meet face-to-face, I would post the questionnaire booklet, survey slip and guidance booklet. I would also like to offer telephone and skype interviews to allow greater access to participants whilst reducing potential inconvenience caused by the interviews.

I would also like to recruit participants via social media as a means of expanding access. This will be through Facebook, Twitter and Instagram. Although these platforms are worldwide, I will only aim to interview those who reside in the UK (the poster attached to these posts will detail this). When recruiting through Facebook, I will locate informal support groups and pages (such as those for carers and family of someone with schizophrenia) and general carer groups, as well as pages ran by relevant charities (e.g. Carers UK and The Carer Trust). I will contact the admin of each page and ask for permission to post some information about the study (see Facebook Post 27.03.2017). This will ask those who are interested to contact me (through my university email address) rather than commenting on the post.

With regards to Twitter, I will use my professional Twitter account to contact relevant accounts, again asking if they would be happy to 'retweet' (i.e. forwarding my initial Tweet). My Tweets will provide a brief summary about the research (under 140 characters) and more information will be included through a picture of the research poster (see Twitter and Instagram post 28.03.2017). I will also use hashtags (#) which mean that these will be visible to those who search for these terms. Examples of these will be #schizophrenia, #severementalillness, #mentalhealth,
#personalitydisorder, #mentalhealth, #bipolar, #carer and #caregiver. Those who are interested will be asked to contact me via university email. Finally, Instagram will follow a similar procedure as Twitter – i.e. I will post an image of my recruitment poster with some written information about the study. I would like to create new Facebook and Instagram accounts so that I will not be using my personal account.

I would also like to contact online support groups for family of people with SMI. I will identify these through the Google search engine and this will follow the same procedure as the Facebook groups/pages.

Finally, I would like to advertise this project online through Citizen Science and Google ads. Citizen science is an organisation where research projects can be advertised (no charge at present). I have located a website for this for Citizen Science Salford (http://www.citizenscientist.org.uk/aboutresearch/) and have contacted asking for more information about advertising on their website. They have replied saying that I would need NHS ethics or University ethical approval. For Google ads, this is completed through 'Adwords'. This is an advertisement which would appear alongside or above search results, according to the website, these are free to apply for and there are charges for each time a user clicks on this (I will pay for this). These charges can be managed in advance and a limit for this can be set. This will need to include an online link for users to select – I would like to have a blog page set up which will provide the participant brief about the study and will ask if users are interested in taking part to contact me via my university email address.

I will send the participation brief to carers who have contacted me indicating interest in the study. If they like to take part, I will post the questionnaire booklet (with a self-addressed envelope of my university address and a stamp included) and ask these to be completed and returned. I will also include a slip with the link and guidance for using the online diary. Following the 6 weeks of online usage, I will contact carers to arrange either a telephone or Skype interview and send the second batch of questionnaires (again through post).

Professionals

With regards to professionals, I will follow a similar process as contacting carers through local carer groups. For instance, I will email these groups with information about the study (e.g. the participant brief) and will ask for this to be disseminated. Those who are interested in taking part will again be asked to contact me via email. I would also like to email professionals who work alongside carers, family and friends of people with SMI with in the NHS. I will invite them to attend a face-to-face, telephone or Skype interview. I will ask them to complete the consent form, baseline information form and will include the interview information form.

I would still like to invite participants to hear am overall summary of the study findings and ask their views on these (these will still be recorded). I will be aiming to have participant recruitment completed by August 2017.

Reasons for Amendment/Change:

I have found that my previous recruitment procedure of holding information sharing seminars has not be effective. I have been experiencing low numbers at these (sometimes with no attendees) and have been struggling to increase attendance. I feel that by applying these changes and using tools such as social media, will increase opportunities to recruit participants and allow access to a wider range of carers residing in the UK.

Anticipated Implications:
I do not think there will be many implications for this change. This will increase access to participants and could potential result in a wider sample. This also allows more methods to contact that can be done at any time that is convenient the carer.

Ethical Considerations

- Users 'sharing' or 'retweeting' my post which may result in this being visible to those outside of the UK – There are limited options in this situation, I will ensure that the poster attached to this flyer will include "Carers, family and friends of people diagnosed with schizophrenia or psychosis who live in the UK". If anyone contacts me who does not live in the UK, they will not be able to participate in this study.
- Contacting potential participants through online support groups – There is a chance that those who participate in online support groups may be distressed or unhappy about a study being advertised through a support group. I will contact the admin of these groups to seek permission before posting.
- People commenting on the post about taking part in the study – If people comment on the post, tweet me about this or send me a private message through these platforms (e.g.
  Facebook Messenger), I will remind them to contact via email in a private message.
- The possibility that someone may be in the room or distractions during the telephone interview/Skype call – I will book the interview and means of contact in advance and before beginning the interview will ensure that the participant is able to talk and happy to continue.
- Difficulties for participants gaining access to the Skype software and technical difficulties on the day of the interview – It is likely that those who select the option for a Skype interview are already familiar with the program. If participants are unfamiliar with this program, there will be telephone interviews available. If technical problems arise on the day that cannot be easily resolved, I will ask if the participant would like to reschedule the interview or continue via phone.
- Participants not attending previously organised interviews – I will send a reminder about interviews beforehand and if a participant does not attend (face-to-face, Skype or telephone), I will contact them asking if they would like the opportunity to reschedule.

References

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TO BE COMPLETED BY THE ETHICS COORDINATOR

Acceptance/Rejection (Circle as appropriate)	Signature:  Name: Maria Martinez
Date:	

Follow-up action passed to:
Reason for Rejection:

FORM TO AMEND AN APPROVED ETHICS PROJECT

Principal Investigator	**Amy Johnson**
Project Title	**Reaching out to carers of friends and family with Severe Mental Illness: A model for an online intervention to improve carer wellbeing and quality of life.**
Project Code (where applicable)	
Date of original ethical approval	**26/10/2016**
Date of amendment request	**07/09/2017**

Description of Amendment:
I would like to interview a participant by email using my university email account. This would consist of the same interview questions (previously approved) and follow the same semistructured interview approach. I would contact the participant to arrange a time and a day for the individual interview in advance, once this is agreed, I would email a reminder several days before to check that this is still suitable.

On the day of the interview, I would email them checking that they are still able to complete this and once they confirm, I will provide an overview of the project so far. This consists of a reminder of anonymity as well as the ability to take breaks, not answer any question they do not wish to, and to stop the interview at any point. I will then email them each question individually (I email them a question, they respond, I email the next one etc.), this will allow me to email prompts or other questions to replies in accordance to the semi-structured interview method.

Once completed, I will thank them for their time and will ask if they have any questions about the debrief sheet (as with other participants this will be posted to them along with the second questionnaire booklet). Following the completion of the interview, I would like to print out the email conversation (to be stored securely as with the other transcripts) and I would like to copy the responses straight into a word document or NVIVO analysis software (without the email address or names to preserve anonymity). As soon as possible (i.e. once the interview is completed and responses have been printed/stored securely), the original messages will then be deleted from my Outlook account. I would like to print the responses (as they are raw data) but will not include

the participant name and email address which, as this is going through email, is likely to be above each response.

As I said that I would like to contact participants again with the themes of this study, for this participant, this is likely to also take place via email. This will follow the same procedure set out above.

Reasons for Amendment/Change:
My participant has stated that due to their caring role, they do not think they will be able to take part in a phone or Skype interview in their residence and has stated that they would be uncomfortable using this elsewhere. Although their situation has recently changed, this may change again and therefore I would like to offer this form of interview just in case. They appear to be confident using and communicating through email and are happy for the interview to take place via this method.

Anticipated Implications:

- There is a chance that the participant may not fully engage in the interview as this will not be held face-to-face. This could lead to smaller responses that take longer to type and send.
- There will be a written record of the interview on both mine and the participant's email account, as this will be performed using outlook each message will have the participants name and email address attached to this. I will delete these emails from my Outlook account once these are printed and stored securely as raw data (these will be printed without the participant name and email address to preserve anonymity).
- This is likely to take longer than the traditional interview format. As this person is a carer, there could be varying delays in responses, ranging from minutes to hours (maybe even responses the following day or a couple of days afterwards), I will allow time for a response and will prompt if this remains unanswered.

TO BE COMPLETED BY THE ETHICS COORDINATOR

Acceptance/Rejection		

(Circle as app	Signature:  Name: Dr Maria Martinez Social work ethics coordinator for Staff and PGR Department of Social work, Education & Community Wellbeing .
Date:28/9/17	

Follow-up action passed to:
Reason for Rejection:

Principal Investigator	**Amy Johnson**
Project Title	**Reaching out to carers of friends and family with Severe Mental Illness: A model for an online intervention to improve carer wellbeing and quality of life.**
Project Code (where applicable)	
Date of original ethical approval	**26/10/2016**
Date of amendment request	**19/01/18**

Description of Amendment:

I would like to contact participants who have previously taken part in my PhD project and ask whether they would like to hear a summary of themes from Individual Interviews to ensure that these accurately reflect their views. Participants were made aware of this process (with many being interested in taking part) and this was included within the Participation Brief and Debrief Sheet.

I would contact each participant (both carer and professionals) via email (or their chosen method of contact) and if they would like participate in this, I would determine a method and time convenient to them. If there is no response from initial contact, I would like to contact once as a reminder. If there is no response after this, I will assume that participants would not like to take part in this phrase of the project.

In terms of method, (similar to individual interviews) these will be email, phone or Skype. Phone and Skype contact will be completed in a booked private room and I would also like to audio record these (just to ensure that any changes are completed correctly). As with interviews, these recordings will be uploaded onto the (password protected) university computer before being deleted from the recorder. If participants would like to complete this via email, these will be printed (without name or email address) and locked in a cupboard with other raw data. There will be no identifying information within this data and participants will only be asked their opinions on the themes presented and whether they accurately reflect their views.

If participants would like to view these via email, I will include these within the body of the email itself (as several had described difficulty accessing and completing word documents through email). Themes will be numbered and if the participant would like to leave feedback, they will be able to reply to the email and match to the number.

These will not be individual themes from individual interviews but overall themes all interviews (separated for carer and professional). Due to time restraints, I will cover themes from carer interviews only to carers, and vice versa for professionals as these were analysed separately.

Reasons for Amendment/Change:

When I originally applied for ethical approval, one of the reviewer comments was whether I would consider presenting sample themes to participants (otherwise known as Member Checking) to ensure validity. When I had included this within my original ethics documents, I had stated that this would be conducted as a group. At that time, this was feasible as I was

recruiting carers of people with schizophrenia or psychosis and professionals who regularly work alongside them, both groups based in the North East of England (particularly Northumberland and Tyne and Wear) however following difficulties in recruitment, I expanded this to carers of people with schizophrenia or psychosis and professionals who regularly work alongside them, within the UK. As such, I do not think it is feasible for this to be completed within a group but will still like to complete this process as a form of validity in qualitative interviews.

Anticipated Implications:
I do not anticipate a lot of negative implications as a result of this process. Participants will be asked whether they would like to hear the summary and will be informed that this will be recorded. If they do not wish to participate, I will thank them for their time and participation and will not pressure them to take part.

I will need to ensure that the results are presented in an easy to understand manner but will encourage participants to ask questions or to let me know if they do not follow. It is unlikely that there will be any distress, this is feeding back results and the initial interviews were exploring experiences of online support and what carers (and professionals) would like to see included within an online intervention. However, if distress occurs, I will direct towards their GP and local IAPT team.

TO BE COMPLETED BY THE ETHICS COORDINATOR

Acceptance (Circle as appropriate)	Signature: Dr Sofia Dedotsi Name: Sofia Dedotsi

Follow-up action passed to:
Reason for Rejection:

Fri 02/06/2017, 14:12

Dear Amy

This email confirms the capacity and capability of ' to be the site for this study. Please proceed.

Please keep me updated with progress and any amendments.

We select a number of projects each year to be subject to audit to ensure compliance with policies etc. so please read the ' policy on record keeping and managing a trial file etc.

Good luck with the project, please use the reference number in any correspondence

Head of Research, Innovation and Clinical Effectiveness

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Faculty of Health & Life Sciences

Reaching out to carers of friends and family with psychosis: A model for an online intervention to improve carer wellbeing and quality of life.

Name of Researcher: Amy Johnson

Name of Supervisor: Dr Markku Wood

Participant Information Sheet

Participant Number

You are being invited to take part in this research study. Before you decide, it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

What is the Purpose of the Study?

Recently there has been an increased focus on providing online support for family members, friends or informal carers of someone diagnosed with schizophrenia, psychosis or bipolar disorder. This study aims to create a model for a new online intervention to try and improve the wellbeing and quality of life of carers, family and friends of someone with severe mental illness. In order to do so, it is important to find out views and opinions about current available support and what would be helpful to include in a new online intervention.

Why have I been invited?

You are an adult (aged 18+) informal carer or family member or friend who provides regular care to someone who has been diagnosed with a severe mental illness (such as schizophrenia, psychosis, bipolar disorder, severe depression and a personality disorder) and have shown an interest in taking part in this study.

Do I have to take part?

No, it is up to you whether you would like to take part in the study. If you do take part, you are free to drop out at any time and do not have to give a reason.

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What will happen if I take part?

If you would like to take part in this study, you will be asked to complete the Carer Booklet which consists of several health and general information questionnaires. These will be sent to you via post, however face-to-face meetings at carer groups or Northumbria University will be available for those who live in . This should take approximately 20 minutes to complete. If you need any help completing the questionnaires or have any questions, please feel free to contact the researcher.

You will then be asked to use online support as you would normally do so for up to 6 weeks and complete an online diary entry (through Bristol Online Survey). You will receive weekly reminders about completing the online survey. After 6 weeks, you will then be invited to an individual interview which will be recorded and we are still interested in hearing your views if you were unable to online support, this is to gather a wide range of opinions.

You will not be asked to provide personal details about yourself or those you care for. If you use online support, you will be asked a series of questions about your opinions of these and how you feel they impacted on your wellbeing and quality of life. If you do not use online support, you will be asked what prevents you from using these and how you think these could be improved. Both groups will be asked about what they would like to be included in an online intervention specifically designed to improve the wellbeing and quality of life of informal carers of people with schizophrenia and psychosis.

The individual interviews will last between 60 to 90 minutes. Once the interview is completed, you will be asked to complete some health questionnaires before receiving a debrief sheet. This explains the nature of the research, how you can find out about the results and how to withdraw your data if you wish. Again these will be sent via post, face-to-face interviews will be available for those who live in .

Later, you will have the option to be contacted by the researcher who will provide an overall summary of the study findings. You will be invited to share your views about these and whether you feel that they are a good representation of your views or needs. Please note, like with the interviews and focus groups, these will be recorded. Your individual scores will **not** be given at this session. Individual scores on the health questionnaires will be given to you, if you have asked to be contacted in the event that you received a high score (see consent sheet).

What are the possible disadvantages of taking part?

There might be a slight inconvenience in travel and time taking to complete the study. You may also feel uncomfortable talking within a group or being recorded, if so, individual interviews are available. You are free to withdraw at any point during or after the study and can also choose not to answer questions which you may find uncomfortable. Any data you provide will be confidential and the recording will only be heard by the investigators and two supervisors.

What are the possible benefits of taking part?

By taking part in this study, you will be contributing to the understanding about current support available to people caring for someone with a severe mental illness. Also by sharing your views and opinions about the intervention plan, you will be helping to develop a model which can be used to create an online intervention aiming to improve wellbeing and quality of life.

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Will my taking part in this study be kept confidential and anonymous?

Yes, all data collected will be confidential, unless the researcher feels that you or others may be harmed if the information is not shared. You will be given an individual code and your name will not be written on any data which we collect, transcriptions of the interview or any reports or documents resulting from this study. The consent forms will include your participant number and your signature, this will be kept separate from any other data that you provide.

How will my data be stored?

All data will be stored in accordance with Northumbria University guidelines and the Data Protection Act (1998). Paper data (which includes consent forms and typed up transcripts from the interview) will be kept separately in locked storage and any electronic data will be saved on a password protected computer.

What will happen to the results of the study?

The general findings from this study will be included in a PhD thesis and may be reported in a scientific journal or presented at a research conference. All data will be anonymized and will not be personally identifiable. You will be invited to attend a group session to discuss the preliminary finding of this study. Findings will also be sent to your local carer group where they will be disseminated to you or displayed on a notice board. Alternatively, if you would like a summary of the findings, please contact the researcher at the email address listed below.

Who is Organizing and Funding the Study?

This project is funded by Northumbria University.

Who has reviewed this study?

The Faculty of Health and Life Sciences Research Ethics Committee at Northumbria University have reviewed the study in order to safeguard your interests, and have granted approval to conduct the study.

Contact for further information:

Researcher email: amy.johnson@northumbria.ac.uk

Supervisor email: markku.wood@northumbria.ac.uk

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UNIVERSITY NEWCASTLE
Faculty of Health & Life Sciences

Reaching out to carers of friends and family with psychosis: A model for an online intervention to improve carer wellbeing and quality of life.

Name of Researcher: Amy Johnson

Name of Supervisor: Dr Markku Wood

Participant Consent Form – Focus Groups and Individual Interviews

Participant Number

Please initial box

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and to ask questions about the study. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without prejudice. ☐

3. I understand that my views will be recorded and listened to by researchers and that individual outcomes will not be conveyed to me, unless risk or high scores on the health questionnaires are identified and I have selected that I would like to know in the event of a high score. I give my consent for the recordings to be made and permission for these individuals to listen to the tape recordings of my views. ☐

4. I consent to the use of anonymised direct quotes in the write up of reports and presentations which could be published. ☐

5. I understand that my personal information (including name) and that of the person I care for will never be associated with the recording. ☐

6. I agree to take part in the above study. ☐

7. In the event that I receive a high score on one or more of the health questionnaires, I would like to receive individual feedback on those scores. ☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

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Faculty of Health & Life Sciences

Reaching out to Carers of Friends and Family with Severe Mental Illness: A Model for an Online Intervention to Improve Carer Wellbeing and Quality of Life.

Name of Researcher: Amy Johnson

Name of Supervisor: Dr Markku Wood (Northumbria University) and Professor John Taylor (Northumberland, Tyne & Wear NHS Trust)

Participant Information Sheet

Participant Number

You are being invited to take part in this research study. Before you decide it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

What is the Purpose of the Study

Recently there has been an increased focus on providing online support for family members, friends or informal carers of someone diagnosed with schizophrenia, psychosis or bipolar disorder. This study aims to create a model for a new online intervention to try and improve the wellbeing and quality of life of carer, family and friends of someone with severe mental illness. In order to do so, it is important to find out views and opinions about current available support and what would be helpful to include in a new online intervention.

Why have I been invited?

You are an adult (aged 18+) and work regularly with carers, family or friends of people with schizophrenia, psychosis, bipolar disorder, severe depression or a personality disorder (for at least 6 months).

Do I have to take part?

No, it is up to you whether you would like to take part in the study. If you would like to take part in this study, you are free to drop out at any time and do not have to give a reason.

What will happen if I take part?

If you would like to take part in this study, you will be asked to complete the Professional Booklet (which will be posted to you) that consists of a demographic questionnaire. You will be invited to attend an individual interview which will be available via telephone or Skype. These interviews will be audio recorded and is estimated will last between 60-90 minutes.

You will be asked about your opinions on online interventions for informal carers, family members or friends of someone with a severe mental illness and the impact of these on carer wellbeing and quality of life. You will also be asked what you would like to see included in an online intervention specifically designed for family and friends of people with a severe mental illness in order to improve their wellbeing and quality of life.

Once the interview is completed, you will receive a debrief sheet, explaining the nature of the research, how you can find out about the results and how to withdraw your data if you wish. Later, you will be invited to attend a group session where the researcher will provide an overall summary of the study findings. You will be invited to share your views about these and whether you feel that they are a good representation of your views. Please note, like with the interviews and focus groups, these will be recorded.

What are the possible disadvantages of taking part?

There might be a slight inconvenience in travel and time taking to complete the study. You may also feel being recorded. If so, you are free to withdraw at any point during or after the study and can also choose not to answer questions which you may find uncomfortable. Any data you provide will be confidential and recording will only be heard by the investigators and three supervisors.

What are the possible benefits of taking part?

By taking part in this study, you will be contributing to the understanding about current support available to people caring for someone with a severe mental illness. Also by sharing your views and opinions about the intervention plan, you will be helping to develop a model which can be used to create an online intervention aiming to improve wellbeing and quality of life.

Will my taking part in this study be kept confidential and anonymous?

Yes, all data collected will be confidential, unless the researcher feels that you or others may be harmed if the information is not shared. You will be given an individual code and your name will not be written on any data which we collect, transcriptions of the interview or any reports or documents resulting from this study. The consent form which you signed will be kept separate from any other data that you provide.

How will my data be stored?

All data will be stored in accordance with Northumbria University guidelines and the Data Protection Act (1998). Paper data (which includes consent forms and typed up transcripts from the interview) will be kept separately in locked storage and any electronic data will be saved on a password protected computer.

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What will happen to the results of the study?

The general findings from this study will be included in a PhD thesis and may be reported in a scientific journal or presented at a research conference. All data will be anonymized and will not be personally identifiable. If you would like a summary of the findings, please contact the researcher at the address listed below.

Who is Organizing and Funding the Study?

This project is funded by Northumbria University.

Who has reviewed this study?

The Faculty of Health and Life Sciences Research Ethics Committee at Northumbria University have reviewed the study in order to safeguard your interests, and have granted approval to conduct the study.

Contact for further information:

Researcher email: amy.johnson@northumbria.ac.uk

Supervisor email: markku.wood@northumbria.ac.uk

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Reaching Out to Carers of Friends and Family with Severe Mental Illness: A Model for an Online Intervention to Improve Carer Wellbeing and Quality of Life.

Name of Researcher: Amy Johnson

Name of Supervisor: Dr. Markku Wood

Participant Consent Form – Focus Groups and Individual Interviews

Please initial box

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and to ask questions about the study. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without prejudice. ☐

3. I understand that my views will be audio-taped and listened to by researchers and the outcomes will not be conveyed to me. I give my consent for the recordings to be made and permission for these individuals to listen to the tape recordings of my views. ☐

4. I consent to the use of anonymised direct quotes in the write up of reports and presentations which could be published. ☐

5. I understand that my personal information (including name) and that of the carers who I work with will never be associated with the recording. ☐

6. I agree to take part in the above study. ☐

_____	_____	_____
Name of participant	Date	Signature

_____	_____	_____
Researcher	Date	Signature

Project Title: Reaching out to carers of friends and family with Severe Mental Illness: A model for an online intervention to improve carer wellbeing and quality of life.

Name of Researcher: Amy Johnson

Name of Supervisors: Professor John Taylor

PARTICIPANT DEBRIEF

1. What was the purpose of the project?

Previous studies have created online interventions for informal carers, family and friends of someone with bipolar disorder, schizophrenia and psychosis, however few have investigated the impact on wellbeing and quality of life. Also, these interventions appear to have focused on carers of people with a specific diagnosis of severe mental illness (such as schizophrenia) as opposed to

The purpose of this study was to develop a model for an online intervention specifically designed to improve the wellbeing and quality of life of carers of someone with severe mental illness. To achieve this, we held interviews to collect opinions of these, including suggestions on what to include in a new online intervention.

2. How will I find out about the results?

If you would like to find out the results of this study, please contact the researcher with your name and email address or phone number. Please be aware that individual results will **not** be given unless you indicted that you would like to be contacted in the event of a high score.

Those who have taken part in the study will have the opportunity to hear a summary of the study findings and will be asked for your views on these. This is to ensure that these are a true reflection of their views. Please note, this will be audio recorded.

3. If I change my mind and wish to withdraw the information I have provided, how do I do this?

If you would like to withdraw your data, you can email the researcher (details included below) within a month of taking part, mentioning your ID number (at the top of the debrief sheet). After 1 month, it may not be possible to withdraw your data as it may have already been analysed.

4. If I am concerned about my mental health after taking part in this study, what should I do?

If you are concerned about your health following the completion of this study, you should contact your GP or alternatively contact your local Improving Access to Psychological Therapies (IAPT) Service.

The results of this evaluation may be published in scientific journals or presented at conferences. All results will be anonymous (i.e. your personal information or data will not be identifiable). All information and data gathered during this research will be stored in line with the Data Protection Act. At no point will your personal information or data be revealed. Insurance companies and employers will not be given any individual's personal information, nor any data provided by them, and nor will we allow access to the police, security services, social services, relatives or lawyers, unless forced to do so by the courts.

If you wish to receive feedback about the findings of this research study then please contact the researcher at **amy.johnson@northumbria.ac.uk.**

This study and its protocol have received full ethical approval from Faculty of Health and Life Sciences Research Ethics Committee. If you require confirmation of this, or if you have any concerns or worries concerning this research, or if you wish to register a complaint, please contact the Chair of this Committee (Dr Nick Neave: nick.neave@northumbria.ac.uk), stating the title of the research project and the name of the researcher:

Appendix 2: Participant recruitment documents

I am looking for friends or family members of someone with a severe mental illness who would like to take part in a study that is aiming to develop a model that can be used for an online intervention. If you are interested in taking part in this study, please email me at amy.johnson@northumbria.ac.uk

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Do you have a friend or family member with a severe mental illness?

I'm looking for carers, family or friends of someone with a diagnosis of a severe mental illness to take part in a study. This study aims to create a model that can be used to develop an online intervention to improve carer wellbeing and quality of life.

To take part in this study, you should;

- Be a UK adult (aged 18+) carer, family or friend of someone diagnosed with schizophrenia, psychosis, bipolar, or a personality disorder.
- Use or do not use online support to help you within your role.

Please do not comment on this post. For more information, please contact:

Amy Johnson at
amy.johnson@northumbria.ac.uk

I'm looking for #carers or #caregivers of people with #schizophrenia or #psychosis to take part in some research, see pic for more info.

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Do you have a friend or family member with a severe mental illness?

I'm looking for carers, family or friends of someone with a diagnosis of a severe mental illness to take part in a study. This study aims to create a model that can be used to develop an online intervention to improve carer wellbeing and quality of life.

To take part in this study, you should;

- Be a UK adult (aged 18+) carer, family or friend of someone diagnosed with schizophrenia, psychosis, bipolar, or a personality disorder.
- Use or do not use online support to help you within your role.

Please do not comment on this post. For more information, please contact:

Amy Johnson at
amy.johnson@northumbria.ac.uk

I'm looking for #carers or #caregivers of people with #mentalhealth #severementalillness to take part in some research, see pic for info

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Do you have a friend or family member with a severe mental illness?

I'm looking for carers, family or friends of someone with a diagnosis of a severe mental illness to take part in a study. This study aims to create a model that can be used to develop an online intervention to improve carer wellbeing and quality of life.

To take part in this study, you should;

- Be a UK adult (aged 18+) carer, family or friend of someone diagnosed with schizophrenia, psychosis, bipolar, or a personality disorder.
- Use or do not use online support to help you within your role.

Please do not comment on this post. For more information, please contact:

Amy Johnson at
amy.johnson@northumbria.ac.uk

I'm looking for #carers or #caregivers of people with #bipolar or #personalitydisorder to take part in some research, see pic for more info

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Do you have a friend or family member with a severe mental illness?

I'm looking for carers, family or friends of someone with a diagnosis of a severe mental illness to take part in a study. This study aims to create a model that can be used to develop an online intervention to improve carer wellbeing and quality of life.

To take part in this study, you should;

- Be a UK adult (aged 18+) carer, family or friend of someone diagnosed with schizophrenia, psychosis, bipolar, or a personality disorder.
- Use or do not use online support to help you within your role.

Please do not comment on this post. For more information, please contact:

Amy Johnson at
amy.johnson@northumbria.ac.uk

INFORMATION-SHARING SEMINAR

A discussion about online interventions and support available to friends and family of someone with schizophrenia and psychosis

Amy Johnson
Post Graduate Researcher
amy.johnson@northumbria.ac.uk

Housekeeping

- Fire drill
- Toilets
- Breaks
- Mobile Phones
- Questions

Introductions

- Amy Johnson and Bryony Stokes
  - Postgraduate Researcher (PhD student) at Northumbria University.
- Let's go around the room
  - Introduce yourself
  - What is your experience of using the internet to help you within your caring role?
  - What you would like to achieve by attending this session?

What is in front of you?

- Information-Sharing Booklet
  - This contains session outline and information covered within the session.
  - Free for you to take and write on.
- Demographic questionnaire and session evaluation form
  - Just to provide some basic information about who attended the session and what you thought about the session.
- Opportunity to take part in a research study
  - Use online support for 6 weeks and attend a focus group or individual interviews to talk about this
  - More information about this at the end of the session.

Timeline of todays sesison

- Talk a little about wellbeing and quality of life
- Talk about the internet in relation to your caring role
- Talk about the research into online support for carers/family members of people with schizophrenia or psychosis
- Talk about online support available through charities and organisations
- Talk about online courses available relating to your caring role
- Talk about mobile phone apps
- Quality assessment – little bit on stigma

Purpose and aims of the session

- To discuss the advantages and disadvantages of using online or internet-based support.
- To discuss how the internet can help within a caring role.
- To discuss current and previous research looking into online support or interventions for family and friends of people with schizophrenia and psychosis.
- To discuss the available online support for family and friends of people with schizophrenia and psychosis.
- To discuss these in relation to wellbeing and quality of life

Definitions

- Talk within your groups
  - What does 'Wellbeing' mean to you?
  - What does 'Quality of Life' mean to you?

- For the purposes of this session
  - Wellbeing is a combination of your emotions (e.g. happiness, hope), your mental and physical health, and your ability to function within your life.
  - Quality of Life is how well you think your life is going (for example, achieving personal goals), your ability to meet needs and your health and wellbeing (both mental and physical).

Advantages of Online Interventions

- Can you think of potential advantages of using the internet?
- How do you think that this can help you within your caring role?

Using the internet in your caring role

- There are a numbers of ways that the internet can be beneficial in relation to your caring role.
  - Get information quickly and easily (e.g. through search engines)
  - Keep up-to-date with current events
  - Enables communication (e.g. Skype, Messenger, Social Media)
  - Easy to access a variety of items (e.g. food shopping, gifts etc.)
  - Entertainment and Enjoyment (e.g. Social Media, Netflix)
  - Easier to get to or work out route to appointments/locations (e.g. Google Maps)
  - Gain opinions quickly (e.g. reviews when purchasing something)
  - Make/check/change doctor appointments
  - Access to online courses (e.g. Open University)

Evidence-based Support

Click to add text

Absalom-Hornby et al. (2012)

- Used a web camera to provide a family intervention
  - Mother and sister at their home
  - 'Tim' who was diagnosed with schizophrenia and was in a forensic hospital.
- This was suited to each family member's needs (for example, information about schizophrenia, stress management and setting goals)
- Results
  - Tim showed a reduction in symptoms (some remained moderate to extremely severe)
  - Family members showed reduced anxiety, insomnia, social dysfunction and depression.
  - Family members showed increased knowledge about schizophrenia and achieved personal therapeutic goals.

Haley et al. (2011)

- Psychoeducation intervention which was held at one location in Ireland but video-streamed to another.
- This provided information on diagnosis, symptoms, behaviours etc.
- Increase in knowledge at both sites.

Glynn, Randolph, Garrick & Lui (2010)

- Website intervention
  - Resource links
  - Discussion board
  - Video education presentations
  - Real-time chats
- Family members showed an improvement in relationship stress
- No results for the person with schizophrenia

Rotondi et al. (2010)

- Schizophrenia Online Access to Resources (SOAR) website
- For people with schizophrenia and their 'supporters'
- Consisted of
  - Educational and reading materials
  - Three online therapy forums
  - Ask the expert
  - Question and Answers Library
  - What's new?
- 3 months – People with schizophrenia showed reduced levels of stress
- 1 year – People with schizophrenia showed an improvement in knowledge of schizophrenia and a reduction in positive symptoms
  - Those who showed a reduction in positive symptoms tended to spend longer on the website and accessed it more frequently.
- 1 year – Informal carers showed an improvement in knowledge about prognosis.

Current and Future Research

- eSiblings (Sin, Henderson & Norman, 2014)
- Lobban et al.
  - Introduction to psychosis
  - Managing positive and negative symptoms
  - Dealing with crisis and difficult behaviour
  - Managing stress
  - Exploring treatment options
  - Discussion about the future
  - Resource directory
  - Jargon terms

Click to add title

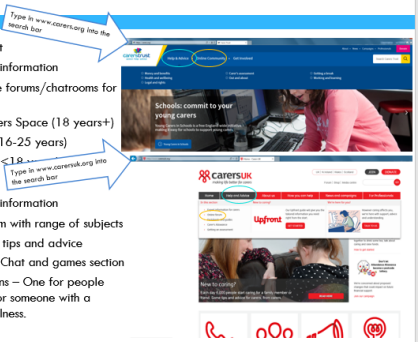
- Task:
  - What do you think of these interventions?
  - What did you like about these?
  - What didn't you like about these?
  - What would improve these?

Available Evidence-Informed Support

- Click to add text

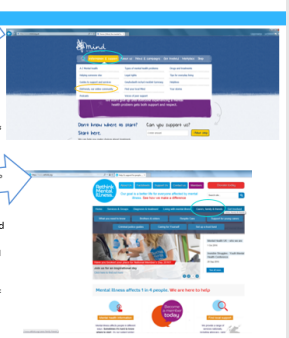
Charities

- The Carers Trust
  - Free online information
  - Three online forums/chatrooms for carers
    - The Carers Space (18 years+)
    - Matter (16-25 years)
    - Babble (<18...
- Carers UK
  - Free online information
  - Online forum with range of subjects
    - Caring - tips and advice
    - Social – Chat and games section
    - Conditions – One for people caring for someone with a mental illness.



Other charities

- Mind
  - Range of free online information about different mental illness and for informal carers (specific section for informal carers of people with schizophrenia and psychosis)
    - Includes access to videos, blogs and podcasts
  - Information about courses
    - Appear to be in London and do charge
  - Online community - Elefriends
- Rethink
  - Range of information about mental illness, section for people with a mental illness and one for family members
    - Section for siblings of a person with a mental illness
  - Information booklets which are free to download (pdf) about how to take care of yourself
    - Self-help and include exercises.



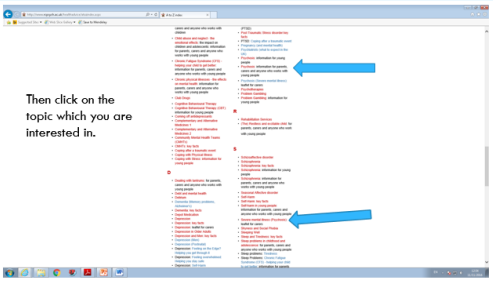
Other useful websites

- The Royal College of Psychiatrists
  - Range of fact sheets are available
    - Schizophrenia
    - Psychosis
    - Severe Mental Illness (psychosis)
    - Carers and Confidentiality in Mental Health
    - Checklists
    - Medication
    - Treatment

Click to add title

Click to add title

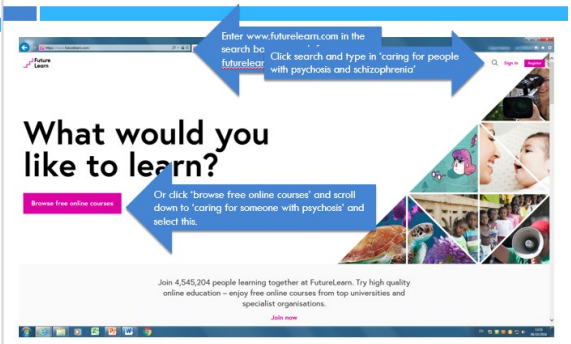
Then click on the topic which you are interested in.

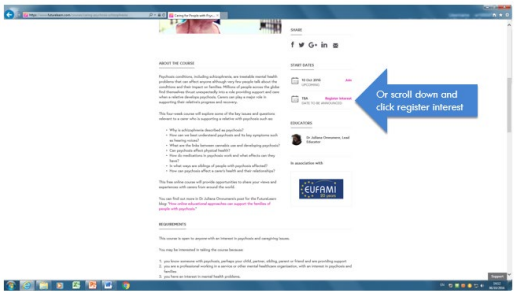


FutureLearn Courses

- Caring for people with psychosis and schizophrenia
  - Free online course created by King's College London provided by FutureLearn (in association with the Open University)
    - This is not a degree qualification but you can print out a certificate of completion (please note, this may involve a charge)
- This course aims to cover common questions and issues experienced when caring for someone with schizophrenia and psychosis.
- Includes information and the ability to comment with each section and to create discussions with other users.

How to access this.





- This is available several times a year (date to be announced) and lasts for a period of 4 weeks
  - The course recommends that you spend three hours a week on this, however you will still have access to the materials after the deadlines to allow you to take your time.
- You will need to sign up to FutureLearn to do this course, this is free to do so.
- There is another course available ('supporting people with long-term conditions') which you can do but this appears to focus on healthcare professionals.

Caring with Confidence

- Online Course – interactive slideshow
- Accessible through internet explorer
- Aims to help informal carers make a difference to their life and the life of those they care for
- Seven topics with up to 8 sections
- Users are able to select what they would like to see
  - Can be completed whenever you want

Click to add title

Click to add title

iTunes university lectures

- These are free to download audio and video educational resources
  - You do not have to own an Apple product to access this, iTunes can be installed onto your PC.
- Provided by universities (including Oxford and Cambridge)
- This can only be accessed through iTunes which will need to be installed onto your computer (or iPhone).
- There is not one specifically relating to your caring role
  - There are several which are about schizophrenia and psychosis and may be helpful.

Examples of iTunes U Episodes

- The University of Oxford
  - Schizophrenia
  - Cognitive Approaches to Treating Psychosis
  - Early Intervention in Psychosis.

iTunes U

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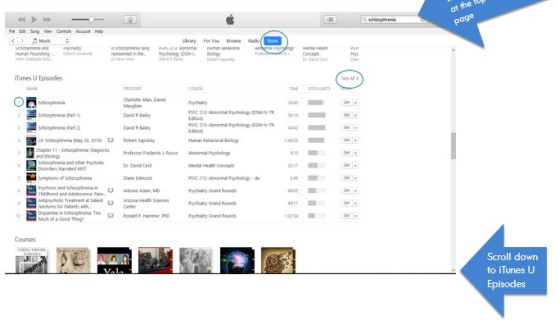

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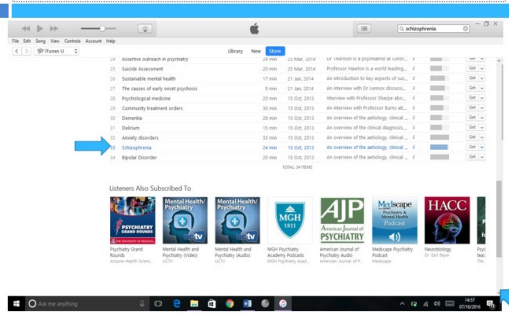
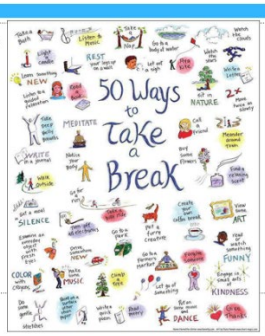


Task

- Write on your post it notes;
  - What do you think of this support?
  - What did you like about these?
  - What didn't you like about these?
  - What would improve these?
- When finished put in the relating corner of the room

Let's take a break…

- Click to



Other Types of Support

Mobile Phone support

- Smartphones are the latest generation of mobile phones
  - Used to be mainly used for phone calls or texting
  - Now able to download and use apps
    - Some are aiming to improve health and wellbeing.

Jointly By Carers UK

- https://www.jointlyapp.com/#welcome
- App developed by Carers UK
- Allows the user to create a 'circle of care', setting up tasks (which can be ticked to show completion) and messages between everyone who is involved in the caring role.
- Uses the calendar to keep track of appointments.
- Has a medication list – current and past.
- This is available online or via both app stores and costs £2.99
  - However you can invite as many people as you want to be a part of that circle of care (or just use it yourself).

Mobile Phone Apps

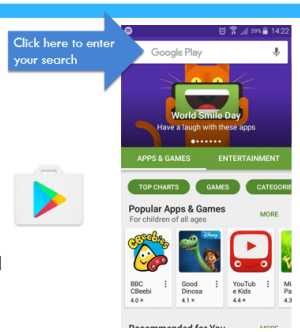
- MoodTools – Depression Aid (by MoodTools)
  - Free mobile phone app.
  - Helps with depression, stress and anxiety
- Five ways to Wellbeing (by Somerset County Council)
  - Allows reflection on, tracking of and activities to promote wellbeing.
- Self-help Anxiety Managements (by University of the West of England)
  - Provides information on anxiety and teaches self-help methods (including relaxation techniques)

Mobile Phone Apps

- Hearing Voices (by Footsqueek)
  - Simulates the experience of hearing voices, interactive activities and podcasts from those with personal experience of hearing voices.
- RCPsych App
  - Access to mental health information leaflets available on websites.
  - Includes podcasts

Google Play Store

- The Google Play Store (or the Play Store) is only available on Android devices.
- To access this, you first need to select the Google Play button
- Once launched, you will have something like this.



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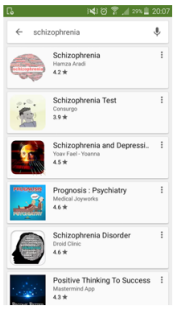
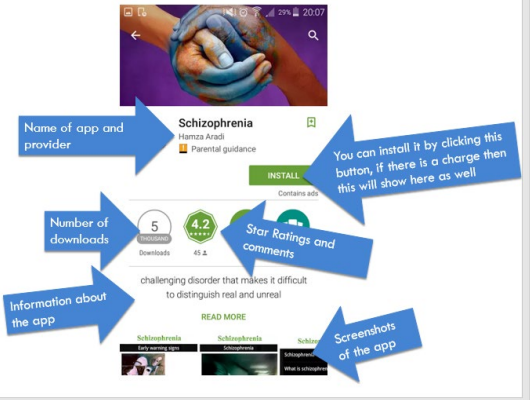
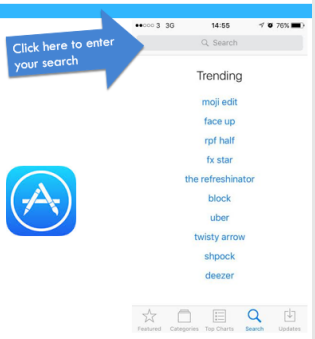
- You may have other options such as 'Entertainment' (books or films that can be downloaded onto your phone)
- But if you select more on the apps option, you will receive a list of available apps such as this.





Apple Store

- The Apple Store (or IOS) is only available on iPhones or via iTunes.
  - iTunes can be installed onto your PC and accessed for free.
- Like with the Google Play Store, you will need to select the button
- Once clicked you will have something like this.



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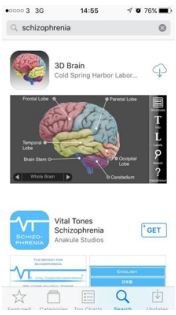
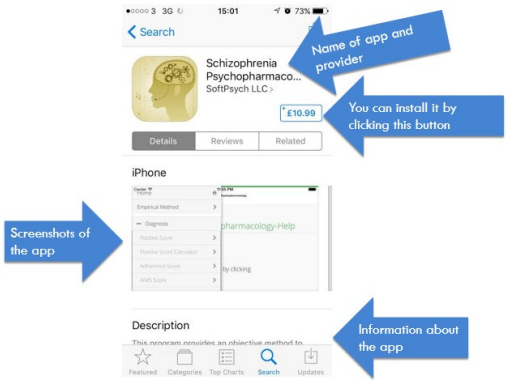
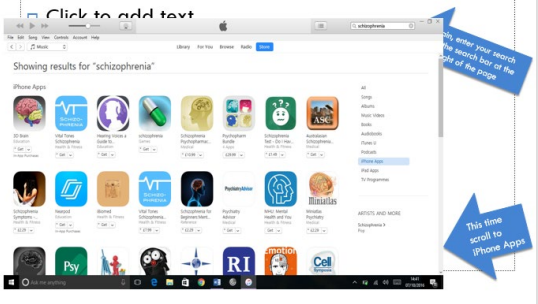
- You will have a list of apps which you can look through and select.





Apple Store through the Computer

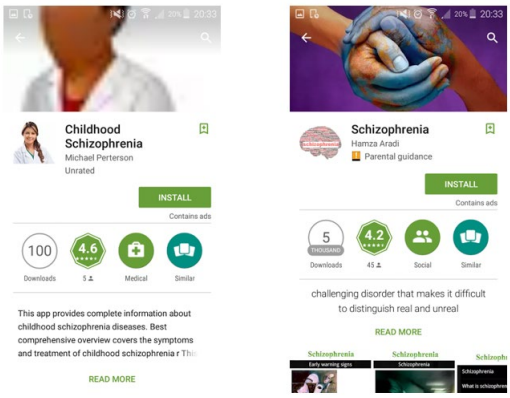


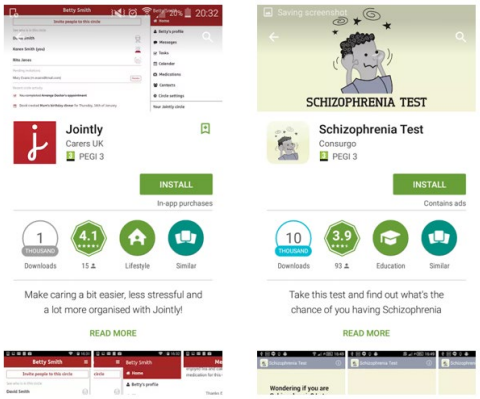
Podcasts

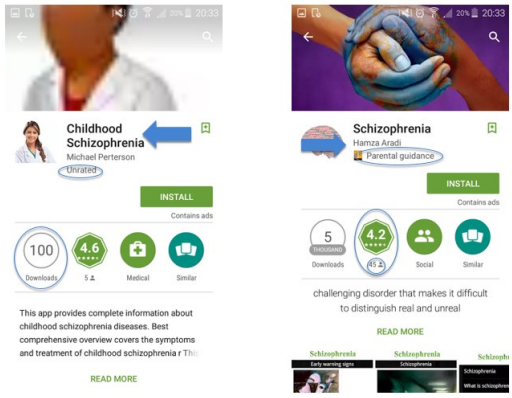
- You can access Podcasts the same way as accessing available apps and iTunes U episodes.
  - You can also access these through other apps or programs (for example Spotify)
- These are similar to the episodes in iTunes U but are not only educational
  - Can include interviews – Alistair Campbell
  - Some includes researchers talking about their current research projects.
  - Others can include people talking about their experiences – people with schizophrenia or their families.

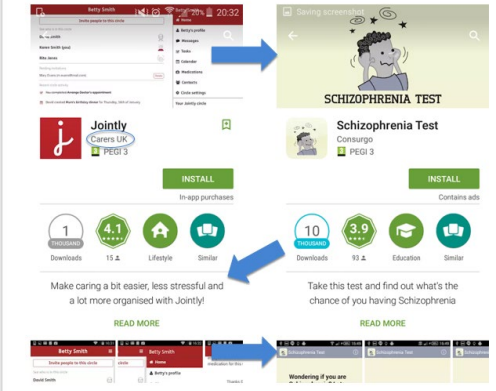
Quality assessment

- It can be difficult determining the quality of online information or mobile apps
  - NHS has attempted to do this, however the webpage is currently under maintenance.
- Task
  - I'm going to show you four different apps and I want you to think about the quality of the app
    - Would you trust this app?
    - What makes these apps trustworthy/untrustworthy?









Quality Assessment

- What is the name of the app?
- Who has developed this?
  - What are their connections/experiences?
- Appearance
  - What is the picture/cover photo?
  - Does the app look professional?
  - Are there any screenshots?
- Information provided
  - Any clinical tools used?
  - Are references included?

Quality Assessment

- How many times has this been downloaded?
- What are the reviews?
  - Star rating
  - Comments
- When was this created/last updated?
- Is there anything else?

Stigma

- Unfortunately this is still a problem
  - Especially online – Apps and podcasts
  - May be regulated by companies, but are not regulated by health professionals
  - As a result, this may be distressing
- You can report these to the company which may result in them being removed.

Reaching out to carers of friends and family with psychosis: A model for an online intervention to improve carer wellbeing and quality of life.

- Carer Booklet
  - Opportunity to take part in a research project aiming to create a conceptual model towards an online intervention to increase wellbeing and quality of life in informal carers of people with schizophrenia and psychosis.
  - **You do not have to take part in this study to attend the session!**
  - To take part, you need to complete the booklet and hand it in at the end of the session. This will take approximately 20 minutes.
    - Participant brief
    - Consent form
    - Questionnaires
    - Consent to contact form – to be invited to attend an interview or focus groups to see whether you used these interventions and what you thought of them.
  - If you have any problems or questions, feel free to ask!
  - Last 15 minutes will be for anyone who would like to take part in this.

ANY QUESTIONS?

Please complete the session evaluation form before you leave.

If you would like to take part in the research study, please hand in your booklet before you leave and I will be in touch.

Information Booklet

Information-Sharing Seminar

A discussion about online interventions and support which are available to family and friends of people with schizophrenia and psychosis

Amy Johnson
Post Graduate Researcher
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Contents

Glossary

Term	Definition.
Apple Store	The Apple store is an online store where you can download apps onto your iPhone, iPod, iPad or Apple Watch.
Android	Android is one of the leading operating systems on mobile phones (in competition with Apple), normally associated with smart phones or tablets.
Apple	Apple is one of the leading brands of mobile phones (in competition with Android), normally associated with smart phones or tablets (iPhones or iPads).
Apps	Apps are programs that can be downloaded onto your device, these can perform a range of actions and be used for a lot of different purposes.
Blogs	Blogs are similar to online articles, they generally consist of someone's personal experiences either during their everyday life or following a specific situation.
Chatrooms/real-time chats	Chatrooms allow real-time communication via written messages between users, often strangers but if accessed through a charity or online course, they will have similar experiences to yourself.
Download	Downloading a document or a program, allows the user to access something that is based online and place it on their PC. This can allow them to use the program or alter/amend the document.
Facebook	Facebook is an example of social media where you can add people as friends, see what they are posting, communicate with them or join groups and meet people with similar interests to yourself.

Family Intervention	This is an intervention that largely focuses on improving communication between people with schizophrenia and their family members.
Forums	Forums promotes communication between users, generally someone will post a question or a comment, which will create conversation. Unlike chat rooms, these do not have to take place in real-time.
Google	Google is an example of a search engine and primarily can be used to search for relevant websites or information about a specific topic. Other uses can be Google Maps (finding a location or planning routes), Google Plus (a form of social media) or to find academic articles (via Google Scholar).
Google Play Store	The Google Play Store is an online store where you can download apps onto your android phone, tablet or smart watch.
IAPT	IAPT stands for 'Improving Access to Psychological Therapies', this supports the NHS in treating people with depression or anxiety.
Intervention	This is a form of treatment, where people complete an action in order to change or improve health or behaviour. For example, families of someone with a recent diagnosis can take part in a psychoeducation intervention to improve knowledge and coping skills.
iTunes	iTunes is a section of The Apple Store where users can download or access audio files, such as music, podcasts or recordings.
iTunes U	iTunes U is a section of The Apple Store, consisting of freely available university lectures which can be accessed or downloaded.
Messenger	Messenger is an application originating from Facebook that allows Facebook friends to communicate with each other privately.

Netflix	Netflix is a company that provides a monthly subscription service, users are able to watch films and TV shows on their computers, mobiles or TVs.
NICE	NICE is the National Institute for Health and Care Excellence, implemented by the NHS, this provides recommended guidelines for treatment and support for disorders.
PDF	PDF is a type of document, which usually cannot be altered, but users can highlight or leave comments.
Podcasts	Podcasts are audio recordings accessible via the internet consisting of information or interviews about a specific topic.
Psychoeducation	This is a form of intervention available for a range of conditions, aiming to educate carers and patients about the disorder and coping methods.
Search bar	A search bar allows the user to type in a search term and finds suitable results.
Search Engines	Search engines are usually a website, allowing the user to search for specific information following the entering of a search term.
Skype	Skype is a program that connects to the user's friends through the internet and allows video or audio calls. There is also the ability to have instant messaging, similar to chat rooms and messenger.
Smart Phones	Smart phones are the latest generation of mobile phones, these are essentially a small portable computer that promotes access to the internet or a range of mobile applications (otherwise known as 'apps').
Social Media	Social media promotes communication and connection between users through a variety of ways; pictures or via text.

Twitter	Twitter is a form of social media where the user can 'tweet' or share things of interest to them. This can be seen by their followers or can be seen by others in terms of hashtags ('#') or tagging another user by using the '@' symbol.
Video Streaming	Video streaming is similar to that used in the video chat within Skype, it is a live video recording which is sent to another user using the internet.
Web Camera	A web camera allows video recording from one location that can be streamed to another location via the internet.
Website	Websites are online pages that can hold information about a topic or be created and monitored by a business.

Purpose and Aims of the Session

This Information-Sharing session aims;

- To discuss the advantages and disadvantages of using online or internet-based support.
- To discuss how the internet can help within a caring role.
- To discuss the current and previous research that is looking into online interventions for family and friends of people with schizophrenia and psychosis.
- To discuss the available online support for family and friends of people with schizophrenia and psychosis
- To talk about online support in relation to your wellbeing and quality of life.

This session also provides the opportunity to take part in a study which aims to assess your usage of online interventions and opinions of these following 6 weeks. If you would like more information about this, please see the Experimental Booklet or ask the presenter for more information. **You do not have to take part in this study to attend the Information-Sharing Session.**

Wellbeing and Quality of Life.

Group Discussion – feel free to make notes in the box below!

What does 'wellbeing' mean to you?

What does 'Quality of Life' mean to you?

For the purposes of this session, wellbeing will be defined as a combination of your emotions (e.g. happiness, hope), your mental and physical health, and your ability to function within your life. Additionally, quality of life will be how well you think your life is going (for example, achieving personal goals), your ability to meet needs and your health and wellbeing (both mental and physical).

Advantages of Using the Internet to help you within your caring role

Group Discussion – feel free to make notes in the box below!

What are the potential advantages of using the internet? How do you think this can help you within your caring role?

There are a number of ways that the internet can help you in relation to your caring role. This can allow us to gather information quickly without even leaving our home. Before the introduction of the internet, we would need to search manually or ask opinions of other people which could take days. Now search engines (such as Google) generate millions of search results in a matter of seconds.

Apps and websites, such as those run by the BBC, allow users to have constant access to the latest news stories and events when they chose to do. These are free to access, regularly updated and are only able to be viewed digitally, as opposed to newspapers, which are only as accurate as when they were printed, have a charge and then have to be

disposed of afterwards. News websites can also be more engaging and often include links to similar topics and information that may be of interest to the user.

Although there were (and in some case, still are) fears that the internet has reduced communication between people, this does not appear to be the case. Programs, such as Skype or Facebook Messenger, actively promote communication between users (who have to be added or accepted by the user) through word messages, audio and video calls. Similarly social media, such as Facebook, allows users to view posts (or 'statuses') by friends and family which allows them to be kept up-to-date and provides opportunity for further communication.

Users also have quick and easy access to a range of items that can be delivered to their home for a small price (and sometimes free). Supermarkets, such as ASDA and Sainsbury's, often allow shoppers to order shopping from their website and then deliver to their homes between a certain time period, that is chosen by the customer. Members of Amazon Prime who live within specific catchment zones can have certain items (generally food) delivered in as little as an hour. Online retailers, such as Amazon and eBay, allow users to view and purchase items online, which are then posted to their home.

This also means that consumers can see previous reviews and opinions about these products. The reviews are left by people who have already purchased the item and leave feedback. While this may not be considered as good as viewing these items in 'real-life', the reviews give a generalised impression about the quality of the product and how well it fulfils its purpose. This can be useful to gauge whether this would be useful for your own needs, however it is worth remembering that these are often not impartial. There will be more information about judging quality later in this booklet.

The internet can also provide hours of enjoyment and entertainment, joining monthly subscription services such as Amazon Prime or Netflix, allows users to watch a wide range of films or episodes. The internet or even game consoles (such as Xbox One and PlayStation 4) has a range of games available which can be played with friends or members of the public. This can promote communication between friends and can also be useful to be used as a break.

With regards to health, several GP surgeries allow people to make, check and change doctor appointments online via your computer or mobile. This also allows the renewing or ordering of repeat prescriptions online, as well as viewing part of your GP health

record. This is free to access as long as you are registered to a GP. For more information, go to http://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/gp-online-services.aspx.

Access to Google Maps can allow users to locate locations within seconds and also allows route planning in advance. Having access to Google Maps on your phone means that this can be done from the comfort of your chair. This can also serve as a hands-free Satnav (by attaching to a mobile holder) and can provide real-time directions while tracking movements (either walking or driving), a lot easier than using a map!

Access to online courses such as the Open University can allow people to complete degree courses alongside their current responsibilities and employment. This follows 'supported open learning', promoting flexibility (ability to work at anywhere and at any time to fit around previous commitments), all-inclusive (providing all materials needed to study), supportive (providing access to guidance and support) and social aspects (tutorials and online communication such as forums). For more information please see http://www.open.ac.uk/about/main/.

Academic Research

Web Camera

Absalom-Hornby et al. (2012) investigated a family intervention that was provided to three family members through web camera; 'Tina' and 'Sam' at home and 'Tim' who was previously diagnosed with schizophrenia and currently in a forensic hospital. The family intervention lasted for 14 weeks, with each session being between 60-90 minutes long. These were suited to each family member's needs and included information about schizophrenia (with a focus on the stress vulnerability model), setting therapeutic goals and agendas, identifying tools and strategies to achieve these goals, stress management and discussions about medication, stigma and symptoms.

Following the completion of the intervention, Tim showed a reduction in symptoms however some still remained in the moderate to extremely severe categories. Both Tina and Sam showed reduced anxiety, insomnia, social dysfunction and depression scores. They also showed increased knowledge about schizophrenia and achieved their personal therapeutic goals. However, the two family members also showed an increased level of

fear and sorrow post treatment, the authors suggest that this may be due to an increased awareness and knowledge about schizophrenia.

Video Streaming

In Ireland, Haley et al. (2011) assessed a psychoeducation intervention in Ireland to 56 relatives, this was presented at one location and streamed to another. This provided information regarding diagnosis (such as symptoms and behaviours), identifying relapse, medications, and information for family members. This study found an increase in knowledge about schizophrenia in both sites.

Websites

There were two 'blended' interventions consisting of both internet and face-to-face components. Lobban et al. (2013) provided a psychoeducational intervention (Relatives Education and Coping Toolkit – REACT), whilst most of the participants completed this face-to-face, this was available as an online option. Topics consisted of an introduction to psychosis, managing positive and negative symptoms, dealing with crises and difficult behaviour, managing stress, exploring treatment options, discussion about the future, a resource directory and jargon terms. Relatives who took part in this intervention showed reduction in distress and increased feeling of support and coping.

Roddy et al. (2015) lead a needs-led intervention and promoted access to the Institute of Psychiatry website (covered below) which included resources, video and links. The intervention also included a crisis plan, information on IAPT services and contact details, sleep hygiene, problem solving skills, emotional processing, goal-setting and discussion bout NICE guideline, psychosis etc.

Although this study only included four caregivers, there was an improvement in carer functioning with reduced levels of psychological distress and depressive symptoms. The time that carers spent engaging in activities which involved planning and motivation also increased following the intervention. Carer coping strategies were shown to be more functional and two reported less difficult in sleeping. Finally, three carers were shown to have met their individual goals, with one returning to fulltime study and two had career plans.

There were two studies which only provided support online, Rotondi et al. (2010) created a website ('Schizophrenia Online Access to Resources' – SOAR) for both people with schizophrenia and their 'supporters' following a four-hour psychoeducation

survival skills workshop. The website consisted of educational and reading materials, three online therapy forums (one for the person with schizophrenia, one for the informal carers and one for both groups), ask the expert, question and answers library and a 'what's new' section.

This study assessed participants at different time points; 3 months, 6 months and a year. The person with schizophrenia showed reduced levels of stress after three months of using the intervention. After a year of usage, they showed an improvement about knowledge of schizophrenia and a reduction in positive symptoms. Those who showed a reduction in positive symptoms tended to spend longer on the website and shown to access it more frequently. The informal carers showed an improvement in knowledge about prognosis after a year.

Similarly, Glynn et al. (2010) created an online intervention (website) which consisted of resource links, discussion board, video educational presentations and real-time chats. Following completion of the intervention, informal carers showed an improvement in relationship stress, there were no results for the person with schizophrenia.

Group Discussion – feel free to make notes in the box below!

What do you think of these interventions?

What did you like about these?

What would improve these?

Available Online Support

Carer and Mental Health Charities and Organisations

The Carers Trust

Website: www.carers.org

Twitter: @CarersTrust

The Carers Trust provides free online information relating to financial matters and benefits, Carer assessment, taking a break from the caring role and going out, health and wellbeing, employment and education, legal information and carer rights. You can also follow The Carers Trust on Twitter, this is a great way of keeping up-to-date and know what is happening.

There are also three online forums and chatrooms available specifically for carers of varying ages; The Carers Space (for those over 18 years old), Matter (for young adult carers aged 16-25) and Babble (for young carers under 18 years old). Qualified social workers who regularly contribute to the discussions every day of the week moderate these, carers are also able to email questions directly if they want to ask about a private matter. There are also regular events (often with a guest who is an expert in the area) and question and answer sessions held on these chatrooms. Finally, these chatrooms are not solely focused on caring responsibilities; there are also general interest ones where people talk about hobbies and interests.

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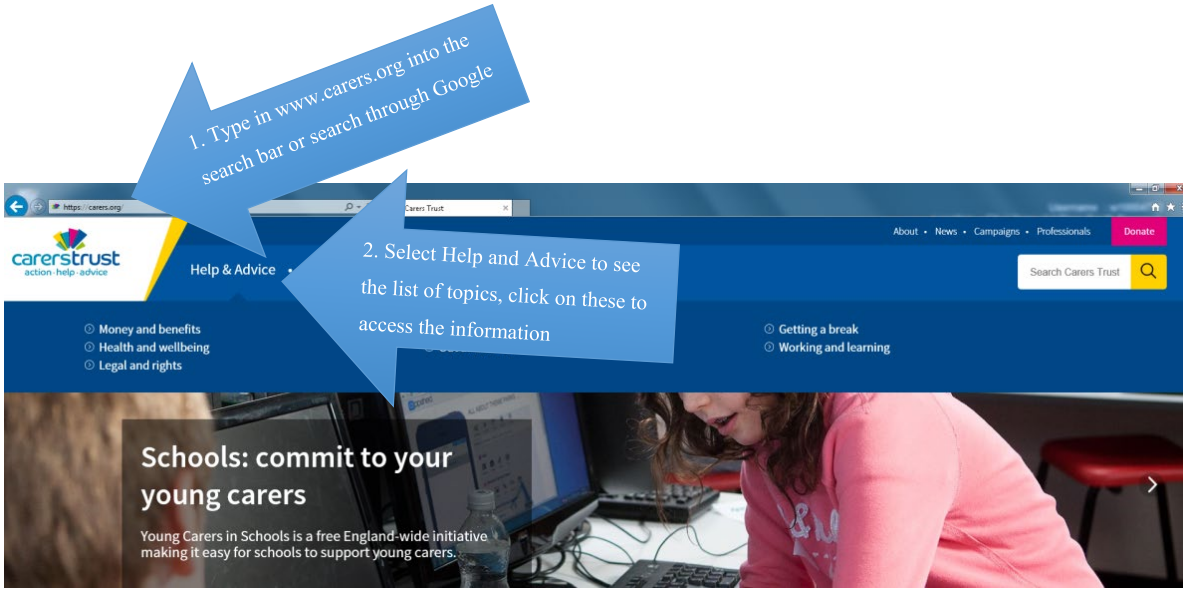

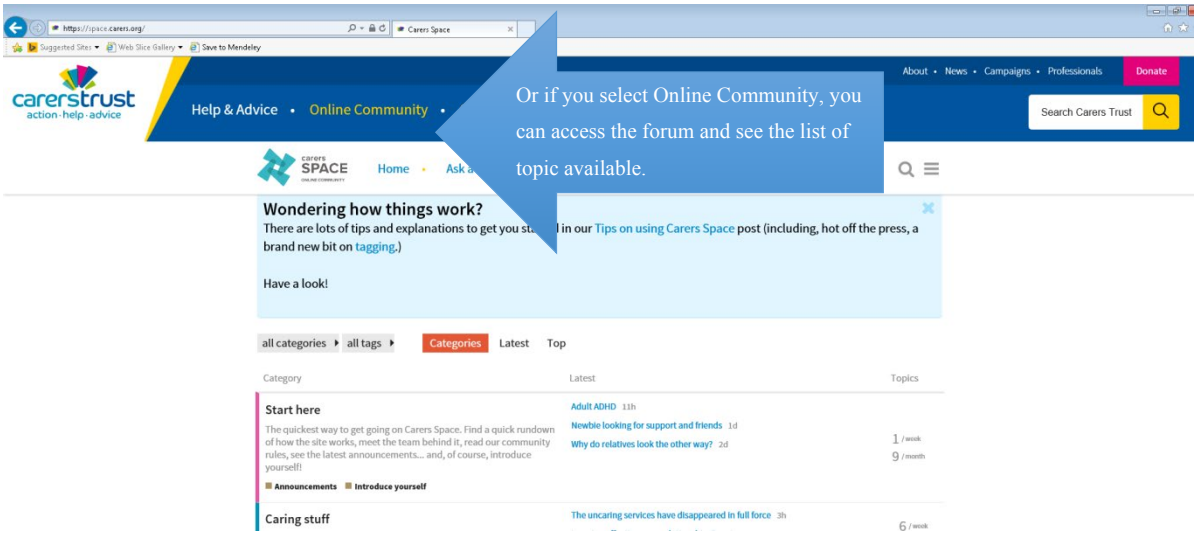

Carers UK

Website: www.carersuk.org

Twitter - @CarersUK

Carers UK provides free online information about financial and practical support, carer health, employment and career, relationships and equipment and technology used to help carers in their caring role. To keep up-to-date with new information and changes, you can sign up to an e-newsletter or again follow Carers UK on Twitter.

The online forum has a range of subjects available about your caring role, including information about caring, tips and advice. There is also a social area to generally chat and connect as well as a games section. There is also a forum specifically for conditions, including one for carers of people with a mental illness.

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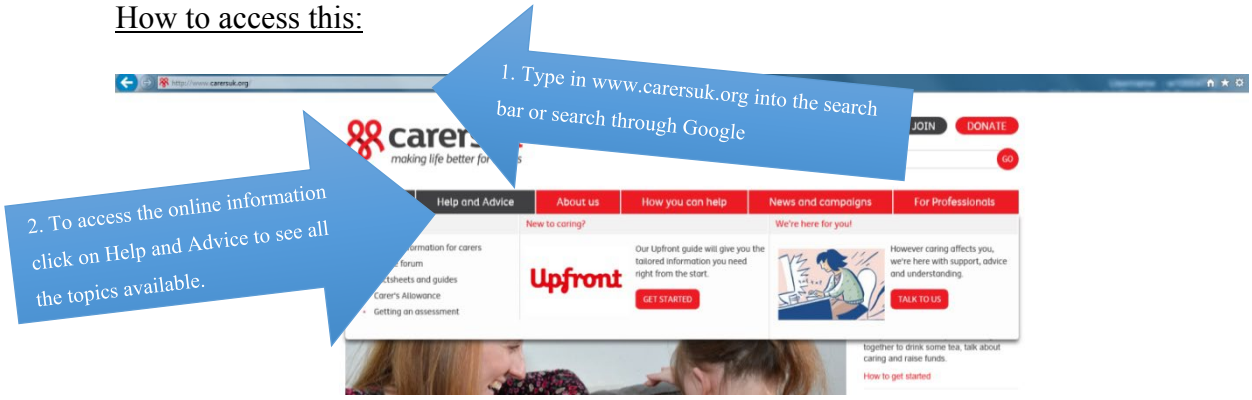


Mind

Website: www.mind.org.uk

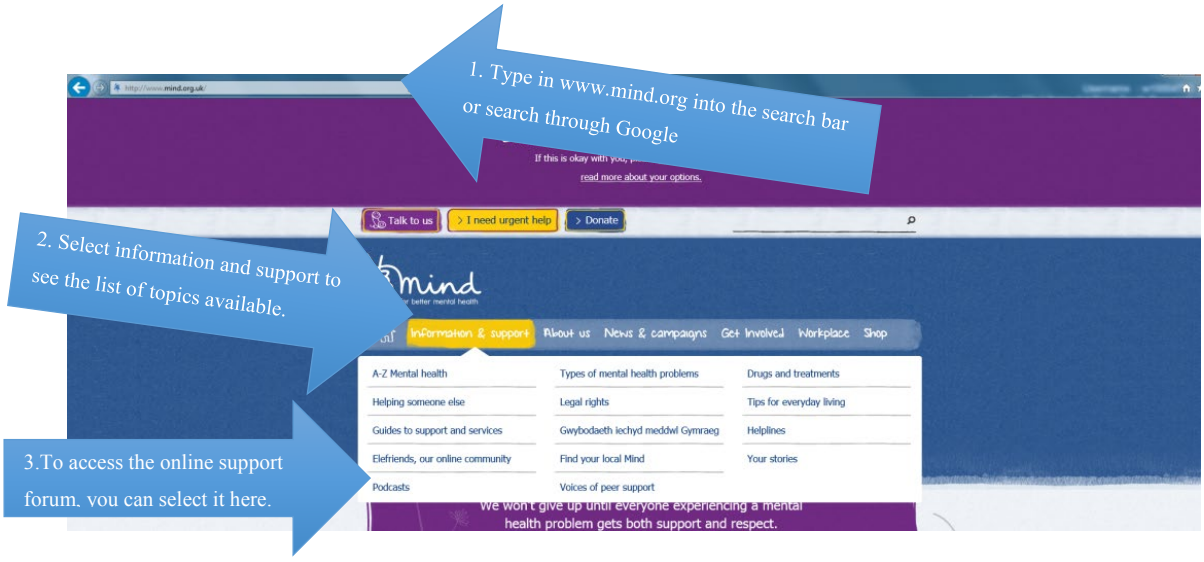
Twitter: @MindCharity

Mind provides a range of information about Mental Health Disorders, for people with a mental illness, for informal carers and the topics relating to them (for example, sleep, diet, schizophrenia and the Mental Health Act). This includes access to videos, blogs and podcasts about individual experience of mental health illness or caregiver experiences. There is free online carer-related information (including carers of people with schizophrenia and psychosis; loneliness, self-esteem, stress, wellbeing, guide to coping and sleep problems).

There is an online community ('Elefriends) which originated on Facebook but is now available on the Mind Website. This is a safe place where you can get advice and support from others and is available as a mobile phone app. This is moderated from 10am to Midnight.

Finally, although Mind does offer courses about mental health (including how to support someone with a mental illness), these are based in London and charge a fee to attend.

How to access this:



Rethink

Website: www.rethink.org

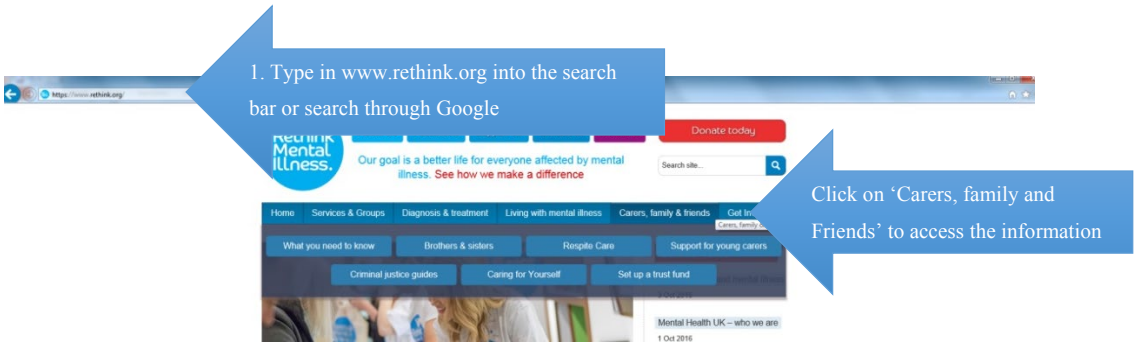
Rethink provides a wide range of information about mental illness and different diagnoses, for people who have been diagnosed with a mental illness and their family members or informal carers. The carer section provides information on what carers need to know (in terms of benefits, Carer Assessments, help in crisis situations etc.), respite

care (gaining funding and how to organise), criminal justice guides and how to set up a trust fund for your relative.

This website provides information for informal carers of varying relationships, for example parents. There is also a large section for siblings of people with a mental illness, including a sibling network, which aims to provide the user with help supporting their sibling whilst also looking after your own wellbeing and access to support groups.

Finally, there is also information about how to care for yourself which consists of 8 downloadable self-help guides (in a pdf format), including information and exercises.

How to access this:



The Royal College of Psychiatrists

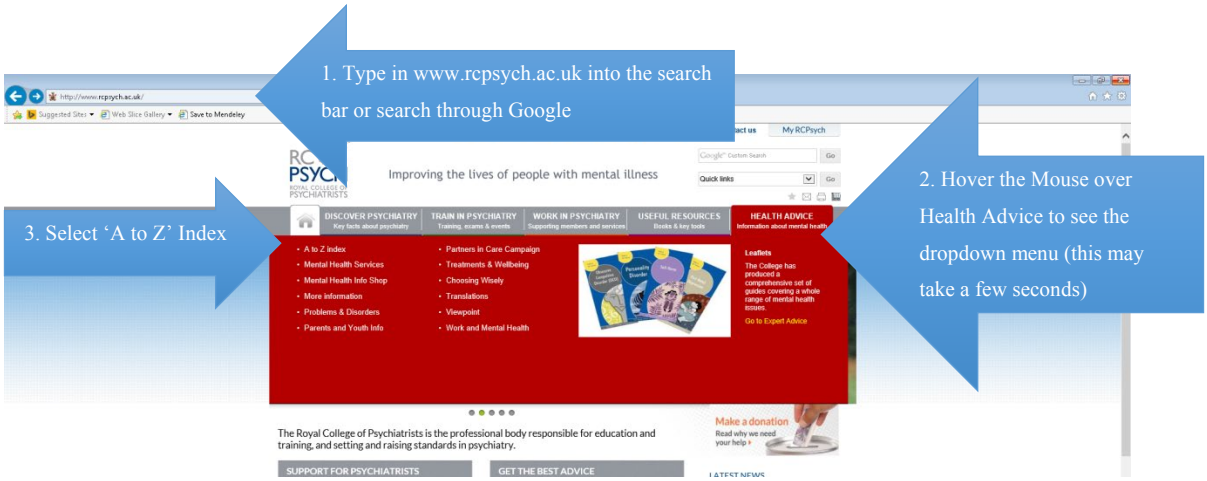
Website: www.rcpsych.ac.uk

Twitter: @rcpsych

The Royal College of Psychiatrists (RC Psych) have fact sheets available for family members and informal carers of people with a range of different diagnosis (e.g. Alzheimers & dementias, Anxiety and Phobias etc.) The Carer's Trust has also worked in association with the RC Psych and have produced some factsheets for informal carers of someone with schizophrenia and psychosis; Severe Mental Illness (psychosis). This provides a range of information about the disorder (such as symptoms, early changes in behaviour and treatments) as well as tips specifically for carers. These tips include advice to develop a partnership with doctor and mental health professionals; questions to ask (including a checklist), tips for during your visit and followup appointments.

There are a range of online booklets that may be helpful; 'Carers and confidentiality in mental health' (although this appears to be mainly directed at mental health

professionals, this discusses the importance of information-sharing, problems and barriers, and examples of overcoming these), a range of checklists (for example, relating to caring or to mental illness), information about medication and treatment (e.g. Cognitive Behavioural Therapy) and information regarding schizophrenia and psychosis (what it is, symptoms, getting help and the future).



You will then see a range of available topics, simply click on the one that you want to view.

Online Courses and Lectures

FutureLearn

Website: www.futurelearn.com

Twitter: @FutureLearn

Hashtag: #FLpsychosis

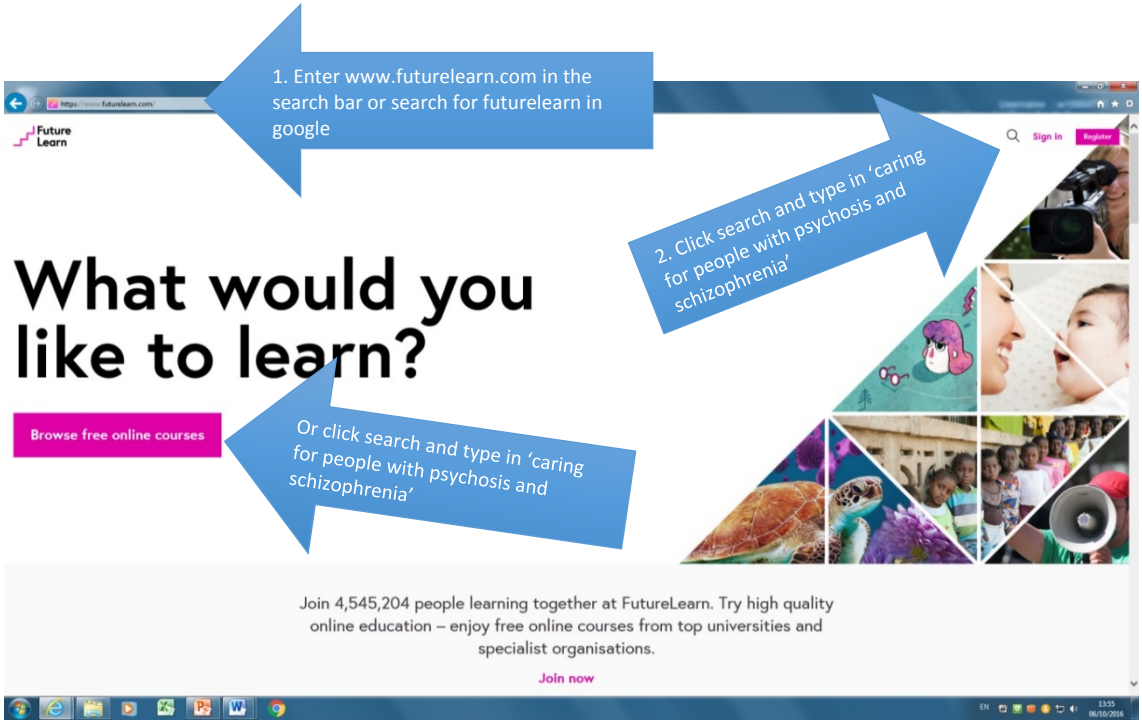
In association with the Open University, FutureLearn has a wide range of courses available. Although not a degree qualification in itself, these are interesting, easy to understand courses and are created by people with known expertise in the topic area.

One of these is '**Caring for people with psychosis and schizophrenia**', this is a course specifically designed for family members or friends caring for people with schizophrenia and psychosis. The course aims to cover issues and questions regarding the caring role and to promote communication with other carers. This was created by King's College London and currently runs for 4-week periods, several times a year, 3 hours a week required.

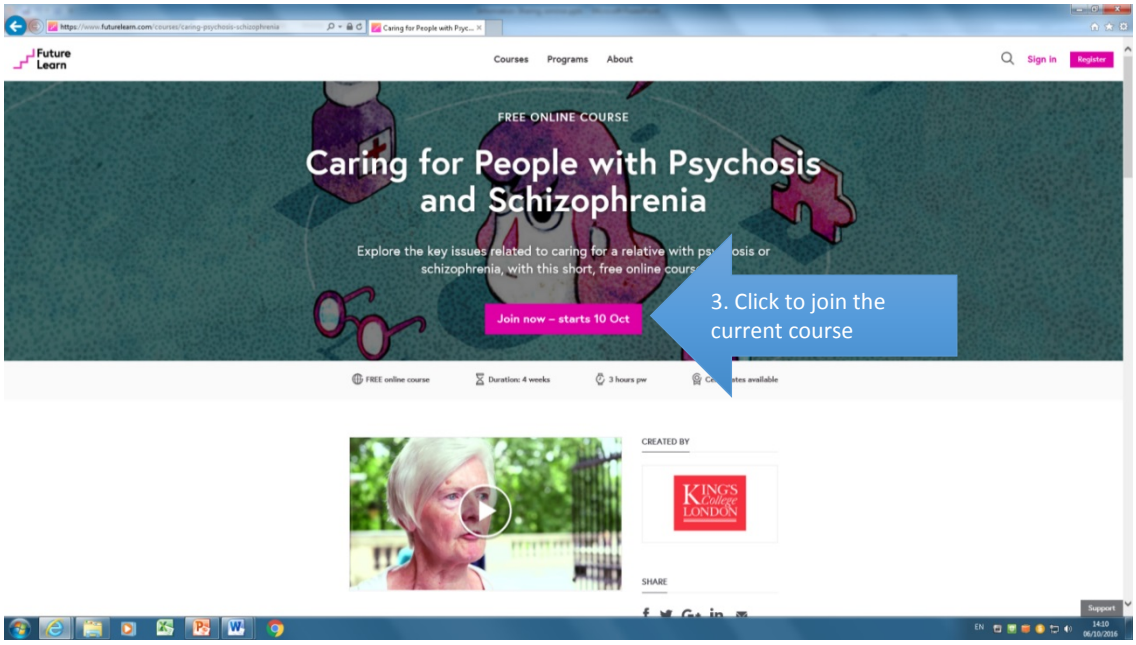
Another available course is '**Supporting people living with long-term conditions**', this is also by King's College London. However, this aims to promote healthcare professional's understanding to support people living with long-term health conditions.

How to access this:

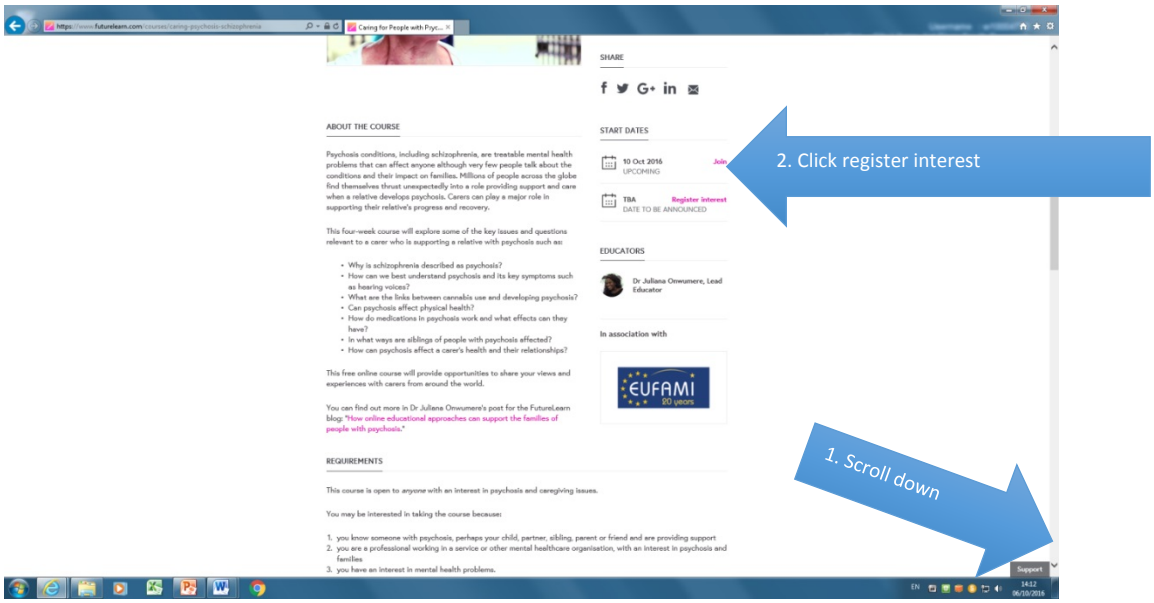
First of all, you will need to open up your internet browser and access the website. This can be done by typing 'www.futurelearn.com' into the search bar at the top of the page or by searching 'futurelearn' in a search engine (such as Google).



This should open up the page of the online course.



Or if this course is not currently running…



Caring with Confidence

Website: http://nhschoices.leopink.com/

This is an online course that aims to help informal carers make a difference to their life that the life of those they care for. These consist of online sessions that teach users simple techniques, resources and notes, and information of organisations that can provide more information and advice. This consists of seven topics with up to 8 subsections, users are able to select which section they would like to view. This is an interactive slideshow presentation which can be completed at the users leisure.

iTunes U

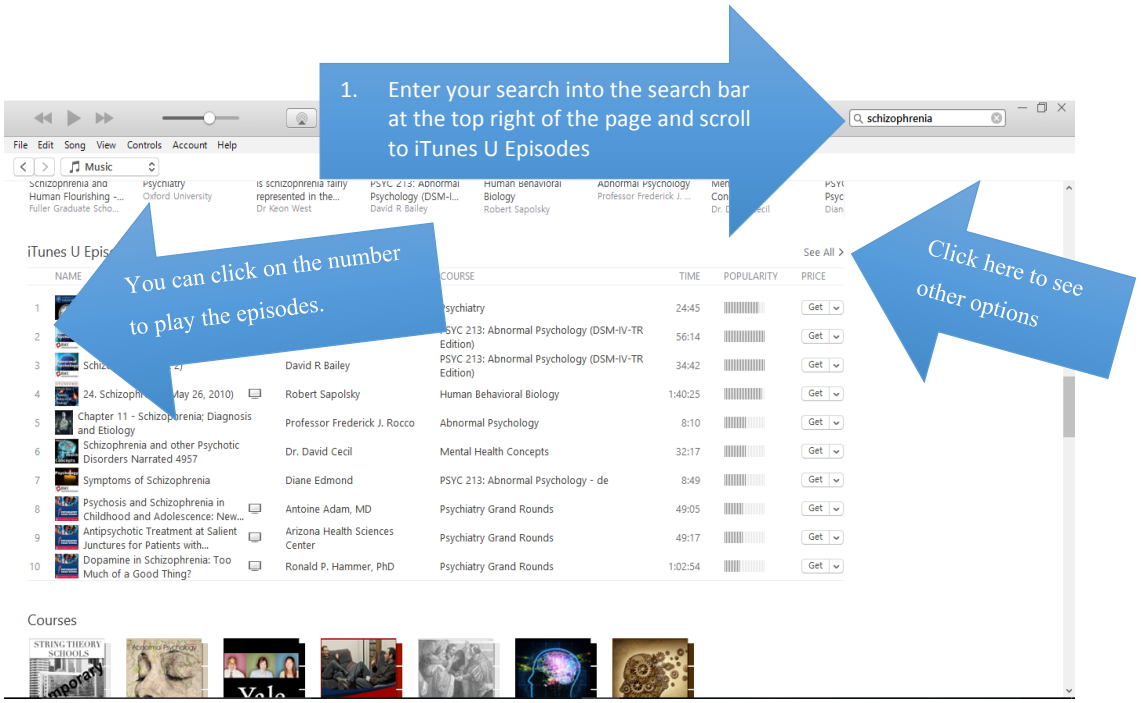
These are free video and audio educational resources available on iTunes and are uploaded by universities and academics, including Oxford University and Arizona Health Sciences Centre. Whilst these may not be specifically relating to your caring responsibilities and may be several years old, a lot of these cover schizophrenia and relating treatments and may still be useful. Additionally iTunes is a free service that you can download and register for regardless whether or not you own an iPhone.

A lot of these don't have information to accompany them, those which do tend to focus on an overview of the diagnosis, management, potential causes, different treatments and update on current research. Some also talk about the current and research being conducted and their findings.

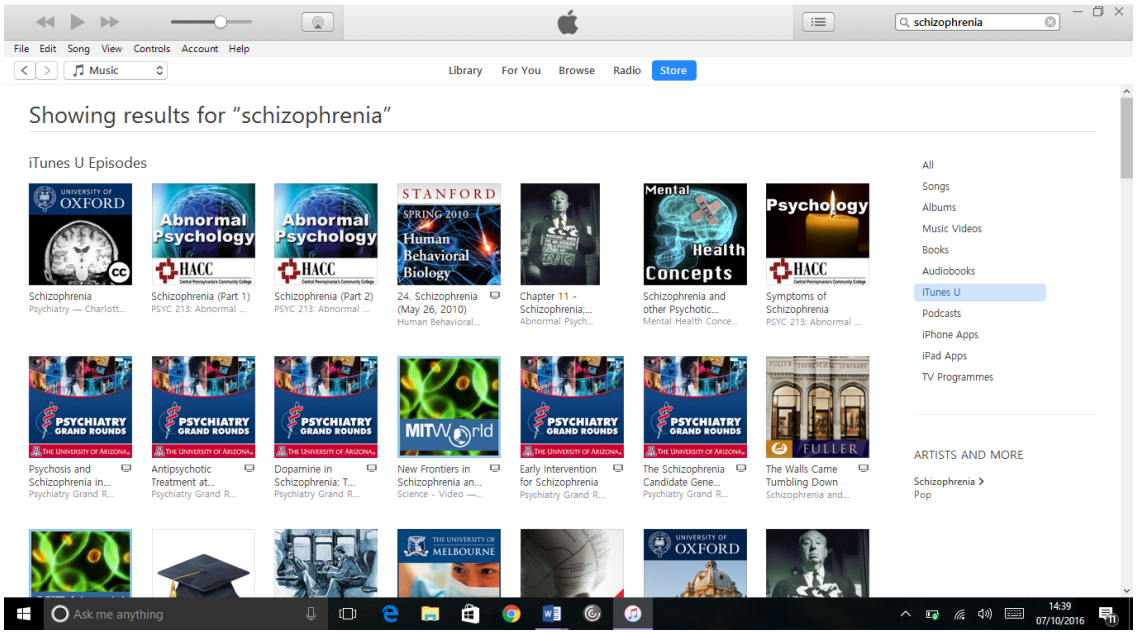
An example of these is **Schizophrenia** by University of Oxford, which provides an overview of schizophrenia, including diagnosis and management. Additionally, Oxford University also uploaded lectures such as **Cognitive approaches to treating psychosis** and **Early Intervention in Psychosis**.

How to access this:

First of all, you will need to install iTunes onto your computer, this is free but you do need to sign up to an Apple account. When you open up the program, make sure that you have selected the store option (highlighted by the blue box on the image below).

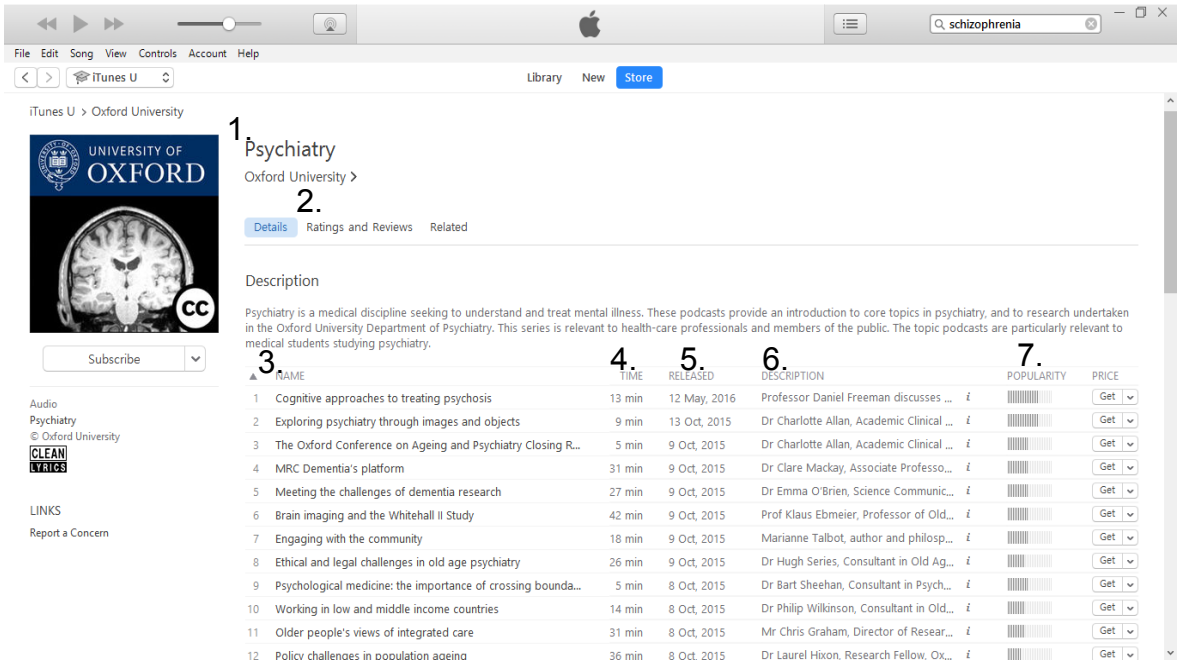


You will see all the available episodes for that search term.



Please note: Abnormal Psychology is a topic in psychology that focuses on thoughts and behaviours that are different from the general public, this is not meant in a negative context.

When you click on an episode that you are interested in, you will get all the episodes that the provider has released;



1. This is the name of the topic and provider.

2. You can click this to see the ratings and reviews of the topic or to leave a review.

3. This shows the name of each episode.

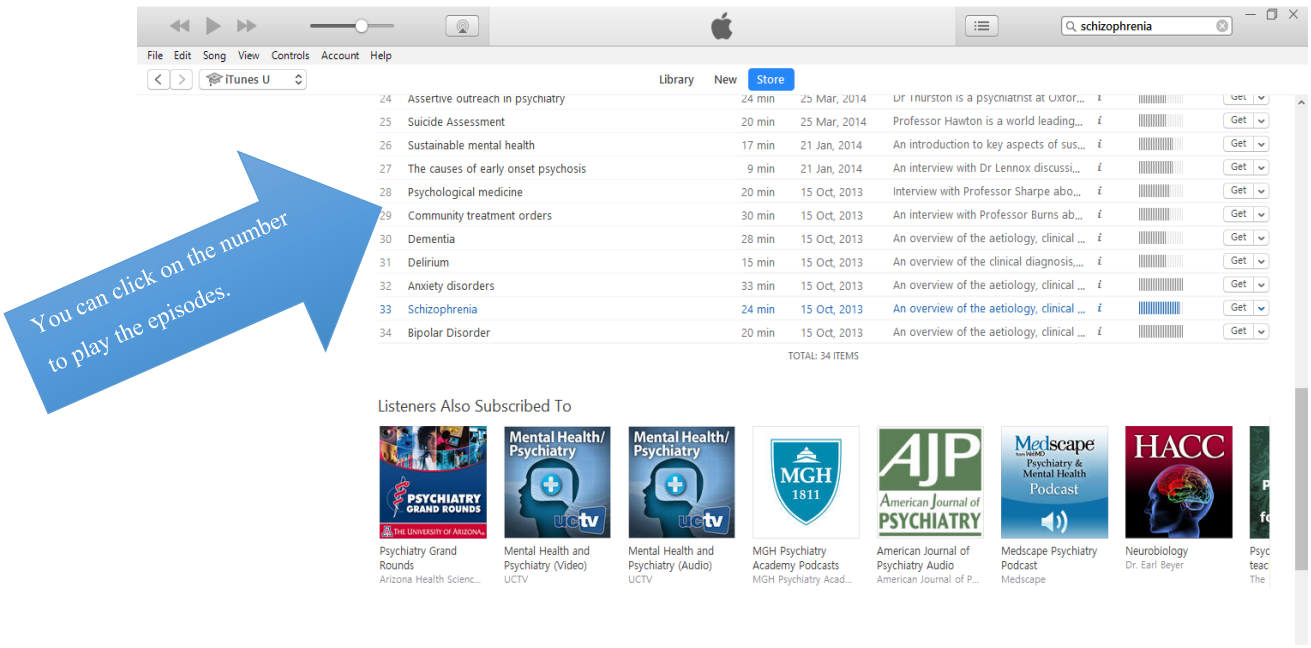
4. This shows how the length of time each episode is.

5. This shows when the episode was released.

6. This provides information about the episode, this is not always provided.

7. This shows how popular the episode is.

If you scroll down the page, you will see the episode you selected is highlighted in blue (although this can vary depending on the background of the page).



Group Discussion – feel free to make notes in the box below!

What do you think of this support?

What did you like about these?

What didn't you like about these?

What would improve these?

Mobile Phone Support

Smartphones are the latest generation of mobile phones and have been described as carrying a small computer around in your pocket. Instead of mainly being able to make phone calls or send texts, now users are able to download and use apps. There is now a wide range of apps available, with some focusing on health and wellbeing, some which may be useful to informal carers of people with schizophrenia and psychosis.

Examples of apps available through both operating systems.

Jointly is an app created by Carer UK that can be accessed through smartphones, tablets or websites. This allows the user to create a 'circle of care' by setting up a list of tasks (those which are completed can be marked off), using a calendar to keep track of appointments, a medication list (both present or past) and allows private messages between everyone who is involved in the care. For further information, please see the website provided at the end of this document.

This is available online through the above website or through both mobile stores. This does have a charge of £2.99, however this only has to be paid once. Once you have access to the app, you can invite as many people as you want or can use it for yourself. You only need one circle of care for the person cared for.

MoodTools – Depression Aid by MoodTools is a free app available on Android and on the Apple Store. This uses research supportive tools to not only help with depression, but also provides support for other situations such as stress and anxiety. This app has over 100,000 downloads and has received a 4.3 star rating.

Five Ways to Wellbeing by Somerset County Council allows reflection on wellbeing and to set activities to improve wellbeing whilst tracking the process. This has been downloaded 5,000 times and has an average rating of 4 stars.

Self-help Anxiety Management by University of the West of England is a psychoeducational app which provides information about anxiety and teaches self-help methods including relaxation techniques. This has been downloaded 100,000 times and has an average rating of 4 stars.

Hearing Voices by Footsqueek is a free app that simulates the experience of hearing voices, interactive activities and also includes podcasts created by people who hear voices. This was created in conjunction with the University of Chester, however there is no further information.

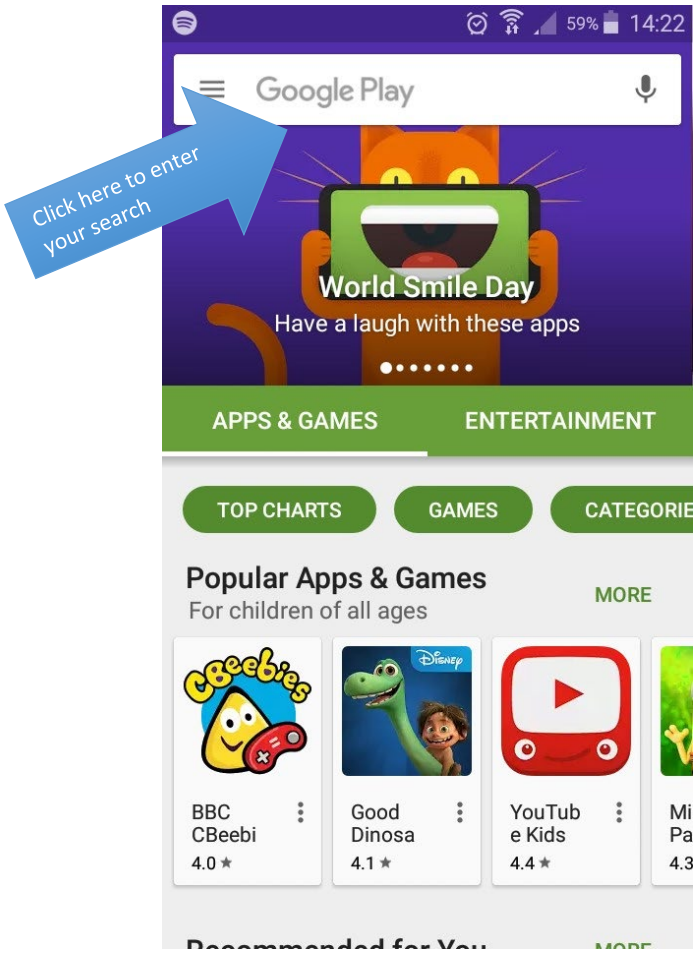
RCPsych App by Melvyn Zhang Weibin allows access to the mental health information leaflets available on the website for carers, mental health professionals and people with mental health diagnoses. This also includes animations and podcasts.

The Google Play Store

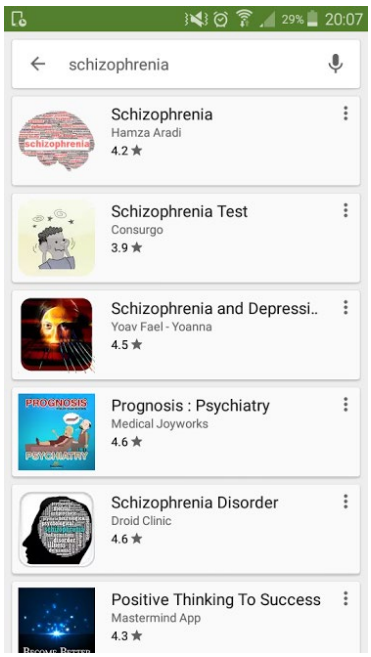
How to access this.

First of all, you will need to select the Google Play Store on your Android Phone.

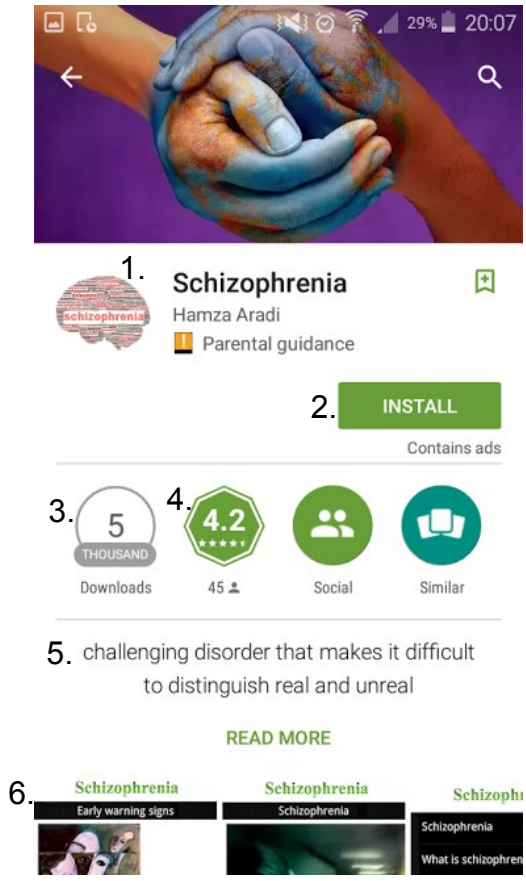
You will then have something like this…



You may have other options such as ‘Entertainment’, these are usually books or films that can be purchased and downloaded onto your device. If you select ‘more’ which is located next to the apps option, you will see a list of available apps;



When you select one of these, you will see a page like this;



1. This is the name of the app and provider.

2. You can install this by clicking here, if the app charges than the price will be here instead of install. This serves the same purpose but will charge to install.

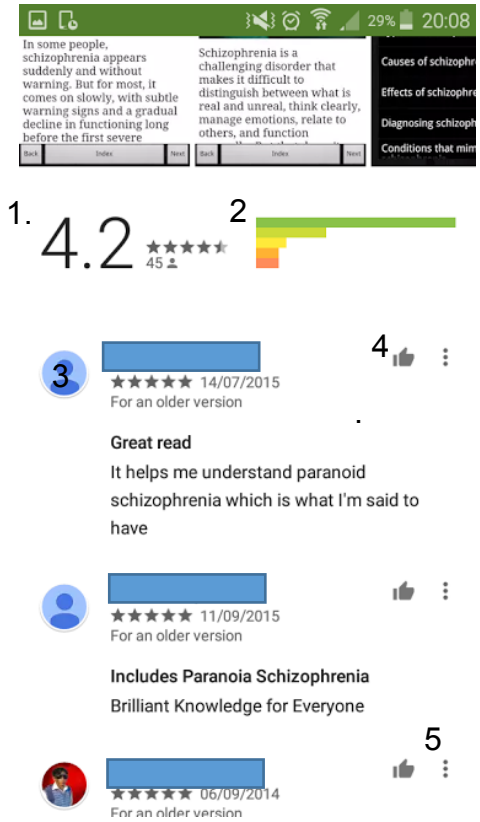
3. This shows the number of times the app has been downloaded.

4. This shows the app star ratings and comments.

5. This provides information about the app, i.e. what is in this.

6. This is screenshots of the app; what the app looks like.

When you select the review option, you will see a page like this;



1. This is the total star rating for the app (usually out of five), the circle next to this shows how many people have reviewed this.

2. This graph gives you shows you the amount of different star ratings.

3. This is the name of the reviewer, the star rating they gave, when they posted and what comment they left. They do not have to leave a comment to review this app.

4. The thumbs up allows you to like the comment.

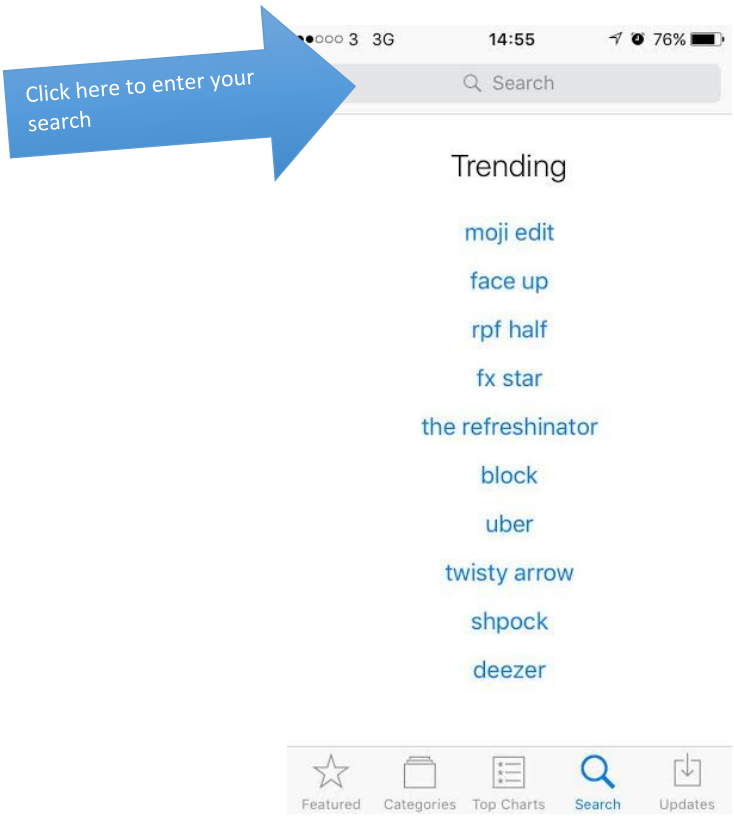
5. This allows you to report a comment as spam.

Apple Store

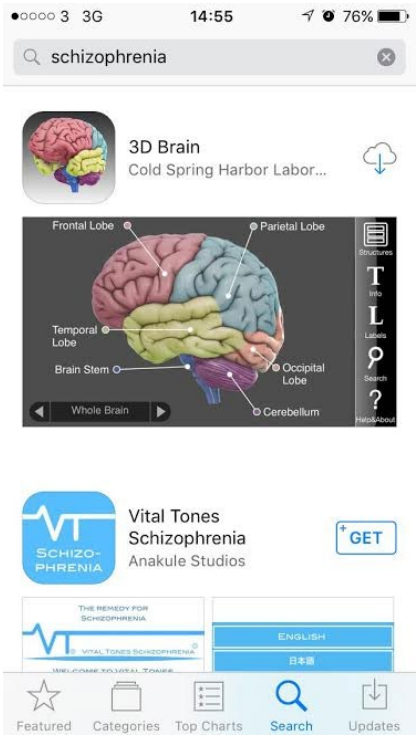
How to access this.

To access this on your iPhone, iPad or Apple Watch, you will need to click on the Apple Store button on you iPhone or iPad.

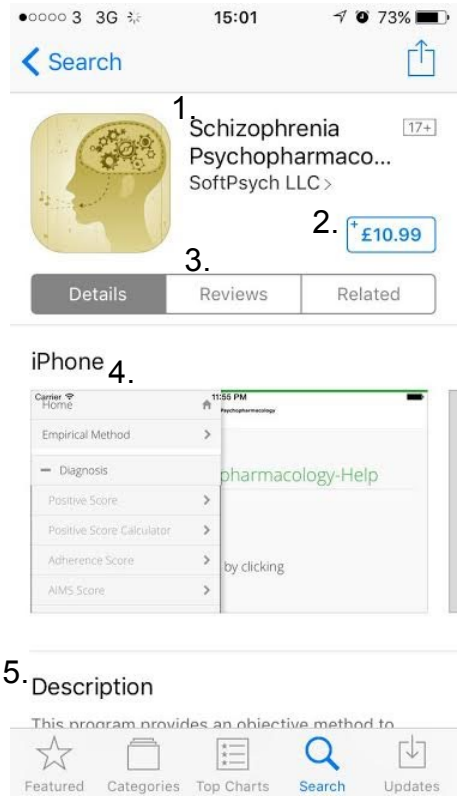
You will then have something like this…



Again, like before you will have a list of apps like this…



The app screen is similar to that of the app store.



1. This is the name of the app and provider.

2. You can install this by clicking here, you can see that this app charges so the price is here instead of install.

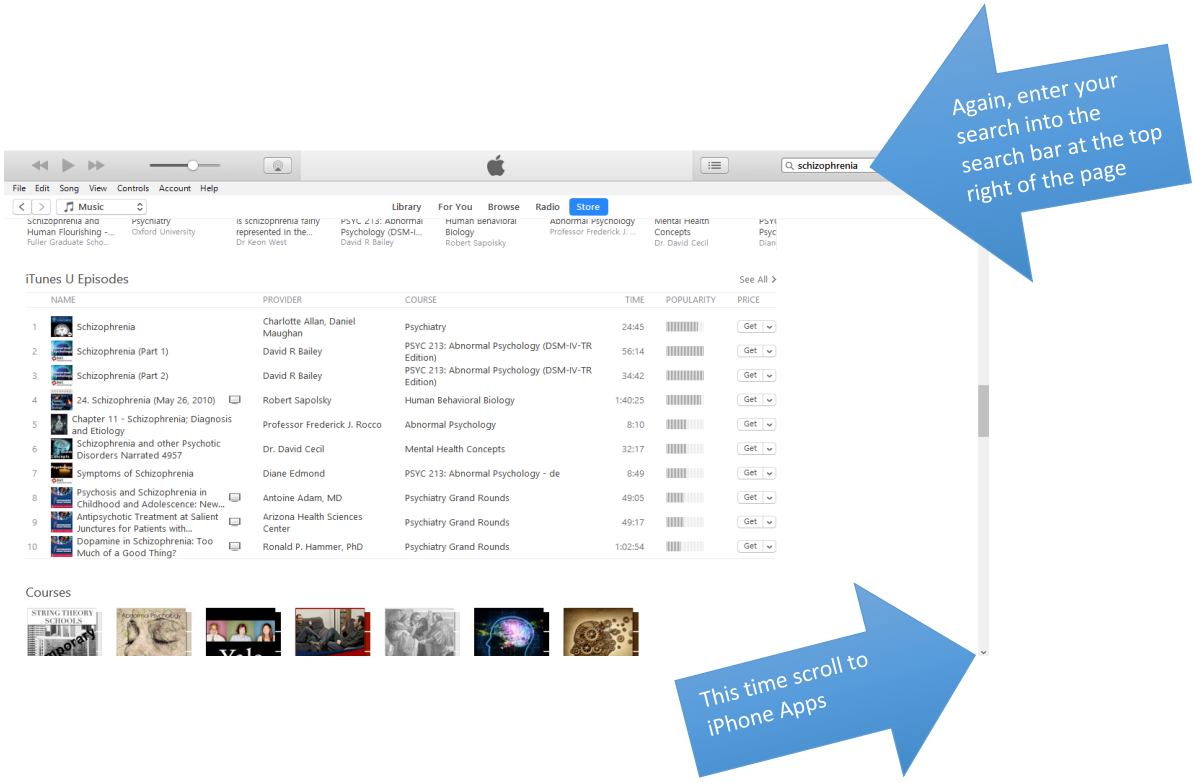
3. You can click here to see previous reviews of this app.

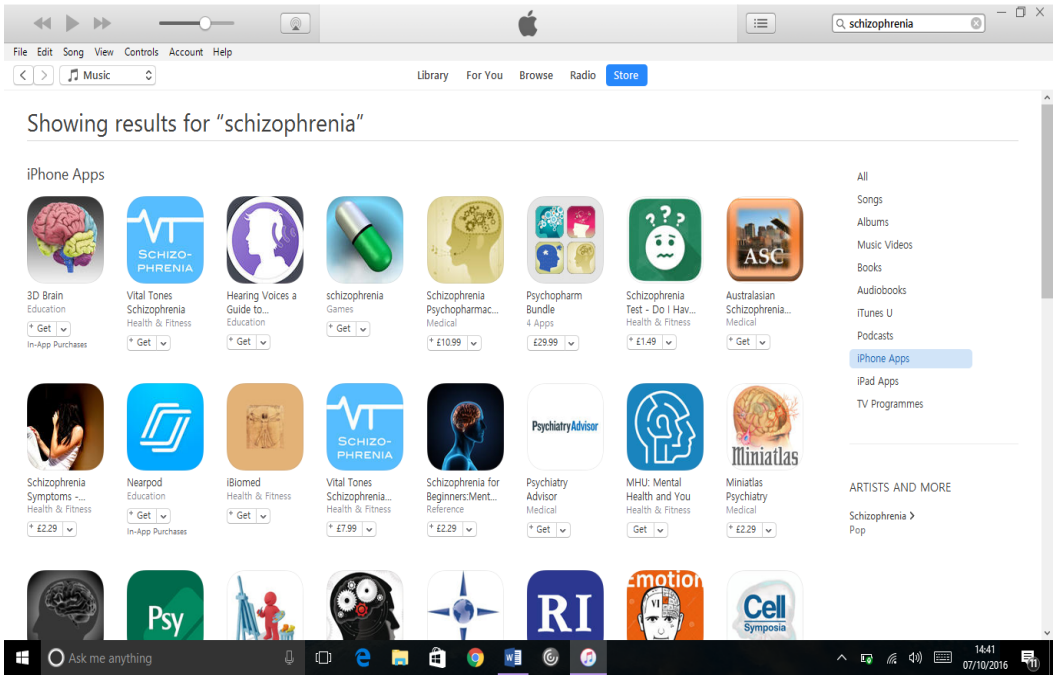
4. This is screenshots of the app; what the app looks like.

5. This provides information about the app, i.e. what is in this.

Accessing this via a computer

Accessing apps is similar to when we previously searched for iTunes U episodes.





You can then select the app and proceed as before.

Podcasts

Podcasts can be accessed through specific apps or programs (such as Spotify). These can also be accessed through The Apple Store by following the same process as described before with mobile phone apps and iTunes U episodes. Similar to iTunes U,

some podcasts can be educational with some uploaded by universities (such as **Schizophrenia** by the University of Aberdeen).

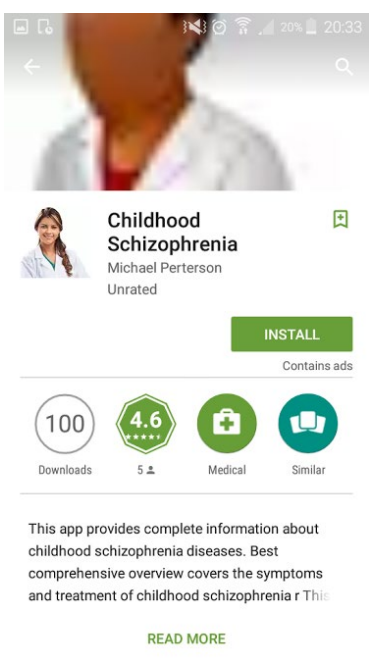
Others can contain interviews, people talking about their experiences and researchers talking about current research and treatment. An example of this is **Schizophrenia** by BBC Radio 5 live, which consisted of an interview with Alistair Campbell about his brother who was diagnosed with schizophrenia.

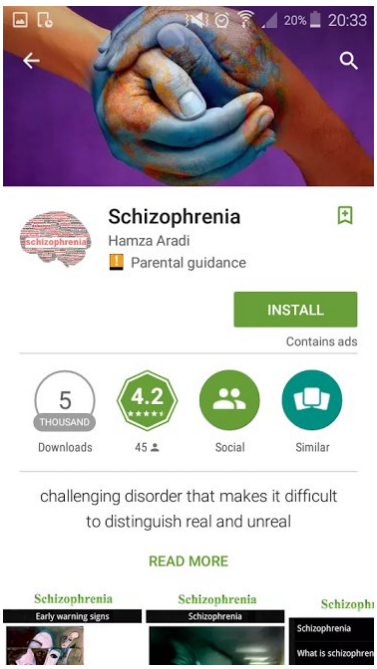
Quality Assessment

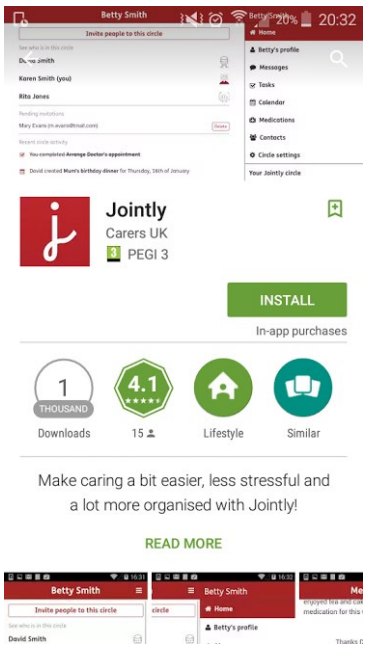
Although support accessed on mobile phones can be very beneficial; carrying a small computer around in your pocket - ability to be accessed anywhere at any time. There can be concerns relating to the quality of using apps. The NHS has information regarding the quality and recommendations of health apps, however this is currently under maintenance (link to this is included in the reference list at the end of this booklet).

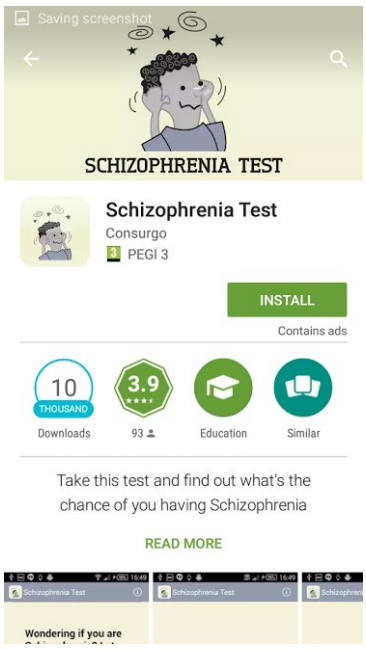
Although there may be some quality assessment by the stores (for example, the Apple Store regulates submitted apps based on technical, content and design), it is important for you to look at the apps and evaluate them in accordance to your own needs.

Look at the images of the apps below;









Group Discussion – feel free to make notes in the box below!

Would you trust the above apps?

What makes these apps trustworthy?

What doesn't make these apps trustworthy?

Please be aware that the above app 'Schizophrenia Test' is not a diagnostic tool.

There are several things which can help you determine the quality of an app or online information;

What is the name of the app/title?

The name of the app often conveys what the focus of this is, which can help you judge whether or not this is useful for your needs. Despite this, it is also important to have a look at the description, often the name of the app does not convey the aims and everything that is included. For example, Jointly does not tell the viewer much information based on its name however the description shows what is included within the app and the potential use for carers.

Who has created this?

It is always important to look at who created the mobile app or wrote the information online. Primarily, what is their experience with the topic? Often experience, viewpoint or background can influence the content provided. It may be useful to research the app or the app provider if you are unsure.

From the images above, one of the screenshots is of 'Jointly' which Carers UK created. Carers UK is a charity which primarily gives support to a range of informal carers who are caring for their friends or relatives. This would suggest that the app would be appropriate and can help you manage your caring role, based on Carers UK's experience working with informal carers.

What is the appearance of the app?

The appearance of the app can suggest whether or not it is appropriate, for example does this look professional? What images are included? As can be seen in the above example 'Schizophrenia Test', the pictures show a cartoon person who appears to be confused, this does not seem as professional as some of the other examples. Finally, screenshots are a fantastic way to see contents of the app to gauge relevance and quality.

What does the description say?

The description section provides information about the content, aims and purposes of the app. This should be clear, concise and easy to understand. When looking at this, it

may be helpful to see if there are any references included with this. References can suggest that this app or information is evidence-based or evidence-informed.

Additionally, if this claims to measure a current state, is this done by using a clinical tool? The above example 'Schizophrenia Test' is **NOT** a diagnostic tool and at the bottom of the description it states that this is used to raise awareness as opposed to diagnosis.

How many times has this been downloaded?

The amount of downloads can be a good indicator of the quality of the app, for instance those which have been downloaded 10,000 times will be seen in a better light than one which has been downloaded 100 times. Whilst this may be accurate, it is important to remember that other factors affect download rate. For instance, when was the app created? If this has recently been released, then it would have less downloads than one which has been available for years. This may not necessarily mean it won't be as helpful as the previous app.

Additionally, it is possible for people to pay to increase their number of downloads to increase their apps appeal. Although this may not be done for malicious reasons, this can affect the reliability of using this to assess quality of the app. It may be useful to use this in combination with the other techniques listed here.

It is also important to remember that often apps from the Apple Store do not provide information on downloads. In this case, the user will need to look at other factors to determine the quality of apps.

What do the reviews say?

Individuals who have downloaded and used the apps leave star reviews that often include comments. The star ratings provide an average view of the app, this is out of five with higher numbers indicating a good rating. However, it is important that you look at how many people have reviewed this app. As can be seen from the top two examples, although 'Childhood Schizophrenia' has a higher star rating than 'Schizophrenia', this only has 5 reviews. This could suggest that 'schizophrenia' may be more reliable because it gives a more generalised review.

Comments left by users can also be helpful as they can highlight strengths and problems with use. Sometimes the developer responds to these and problems can be resolved in

the next update. Again, it is possible for people to pay to get ratings and comments left for the app which can affect the reliability of this method.

When was this created/last updated?

In terms of information, the most up-to-date is considered the most useful. Attitudes and knowledge about a diagnosis can change overtime and it can be important to remain up-to-date. Additionally, with regards to the operating system, updates can allow an app to run smoothly with limited problems.

Is there anything else?

Is there anything else that concerns you about the app or information? As can be seen in the above example 'Childhood Schizophrenia', this is marked as unrated which raises questions about the quality. Additionally, 'Schizophrenia' recommends parental guidance which leads to questions about the content. However, this could just be a precaution as the information may be distressing to younger users who suspect they may have a schizophrenia or psychosis diagnosis.

Stigma Online

Unfortunately, stigma towards a mental health diagnosis (especially schizophrenia or psychosis) remains a problem, especially online. Although the companies may regulate apps, these are often not regulated by health professionals. As previously stated, the NHS has a list of reviewed health apps, which would be a useful resource.

Some apps and podcasts can be insensitive or stigmatize schizophrenia and psychosis, which can be distressing to yourself or the person you care for. There is an option to report apps if you are concerned which may result in them being reviewed and potentially removed.

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Rotondi, A. J., Haas, G. L., Anderson, C. M., Newhill, C. E., Spring, M. B., Ganguli, R., Gardner, W. B. and Rosenstock, J. B. (2005) 'A Clinical Trial to Test the Feasibility of a Telehealth Psychoeducational Intervention for Persons With Schizophrenia and

Their Families: Intervention and 3-Month Findings', *Rehabilitation psychology*, 50(4), p. 325.

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University of Oxford *The University of Oxford on iTunes U*. Available at: https://www.ox.ac.uk/itunes-u?wssl=1.

Appendix 3: Carer and professional questionnaire, weekly diary, carer and professional interview topic guides

Submission (ID: 295256657) receipt for the submission of /fac/med/research/platform/wemwbs/researchers/register

N no-reply@warwick.ac.uk
Thu 23/06/2016, 14:10
amy.johnson

Reply

Thank you for completing this registration. You now have permission to use WEMWBS in the manner detailed in your submission.

Question: Name:
Answer:
Amy Johnson

Question: Email address:
Answer:
amy.johnson@northumbria.ac.uk

Question: Institution/Organisation
Answer:
Northumbria University

Question: Name:
Answer:
Lina Gega

Question: Email address:
Answer:
lina.gega@northumbria.ac.uk

Question: Institution/Organisation
Answer:
Northumbria University

Question: Type of Study
Answer:
Intervention study (WEMWBS before and after)

Question: Description of proposed project:
(For translations, please state the language concerned)
Answer:
On the basis of a recently completed systematic scoping review, we will conduct a series of seminars to inform carers of people with psychosis/schizophrenia about online and mobile-delivered interventions that are designed to help them improve their wellbeing and care for their relative. During these seminars we will discuss the evidence base and quality of these interventions and we will encourage carers to appraise and use them. The carers will be invited to participate in follow-up focus groups and interviews after 6 weeks from when the seminars took place. The purpose of the focus groups and interviews will be to identify whether carers have used any of the online/mobile resources and what they found helpful/positive or unhelpful/negative. We will collect standardised outcome measures of carers' wellbeing (including the WEMWBS) at baseline and at 6 weeks post-seminar. We will use the results of our focus groups and outcome measures to construct a conceptual model which can be used in the design of technology-mediated interventions (both standalone and blended) that support carers of relatives with psychosis to improve their wellbeing and the outcomes of the person they care for.

Question: Description of participants
Answer:
Informal carers of people with schizophrenia and psychosis

Question: Location
Answer:
North East England

Question: Gender
Answer:
Male and Female

Question: Ages
Answer:
18+

Question: Approximate Start Date
Answer:
01/10/2016

Question: WEMWBS version
Answer:
14 items

Question: Expected number of people to be studied
Answer:
20

Question: Other information as relevant
Answer:

Question: Are you willing for us to share top level details of your research
Answer:
Yes

Reply | Delete Junk | •••

Action Items

Dear Amy,

You are welcome to use the scale. Please do let me know how you get on with your research and what you find out.

Best wishes,
Stephen

Professor Stephen Joseph
School of Education
Dearing Building, Jubilee Campus
University of Nottingham,
Nottingham NG8 1BB, UK

http://www.profstephenjoseph.com

NEW: Second Edition of Positive Psychology in Practice
http://www.wiley.com/WileyCDA/WileyTitle/productCd-1118756932.html

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From: amy.johnson [mailto:amy.johnson@northumbria.ac.uk]
Sent: 23 September 2016 20:38
To: Joseph Stephen <lqzsj@exmail.nottingham.ac.uk>
Subject: Permission to use AC_QoL

Hello,

I am a PhD student at Northumbria University and I would like to ask for permission to use a psychometric scale that you and Hannah Elswick developed to use in my PhD project. Just to give a bit of context, my thesis is focusing on online support and the effect on wellbeing and quality of life of informal carers of people with schizophrenia and psychosis.

I would be grateful if you consider this request.

Many Thanks

Amy

Amy Johnson
Post Graduate Researcher
Faculty of Health and Life Sciences
Room CO24
Coach Lane Campus
Northumbria University
Newcastle upon Tyne

Reaching out to carers of friends and family with psychosis: A model for an online intervention to improve carer wellbeing and quality of life.

Carer Baseline Information

Participant Number

Gender: _____

Age: _____ Years

Ethnicity: _____

Highest level of education

- Primary Education or less ☐
- Secondary Education ☐
- Higher education ☐
- Other ☐

Occupation

- Employed ☐
- Self-employed ☐
- Retired ☐
- Unemployed ☐
- Other ☐

Other (please state):

Your living arrangements:

Living alone ☐

Living with others (including care recipient) ☐

Living with others (not including care recipient) ☐

Who do you provide care for? (Please tick)

Wife / Husband / Partner ☐

Mother / Father ☐

Sister / Brother ☐

Daughter / Son ☐

Friend / Other ☐

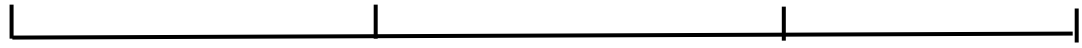
Other (please state):

How old is the person you care for?

_____ **Years**

What is the diagnosis of the person you care for?

Over the past 2 months, how well has your friend or relative been?



Not at all | Not very | Quite | Very

How long have you held a caring role for your friend or relative?

< 1 year	☐	1-2 years	☐
2-5 years	☐	5-10 years	☐
10-20 years	☐	20+ years	☐

On average, how many hours a week do you spend within your caring role?

< 5 hours	☐	5-10 hours	☐
10-15 hours	☐	15-20 hours	☐
20-30 hours	☐	30+ hours	☐

Are you currently receiving support to help you within your role?

Yes	☐	No	☐

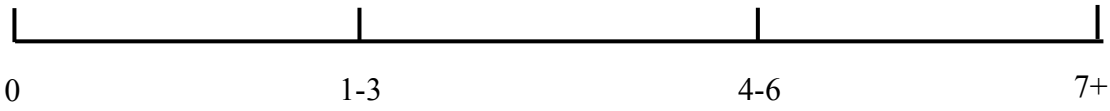
If yes, please specify:

Do you use the internet/online support to help you in your caring role?

Yes	☐	No	☐

If so, what do you use?

If you use the internet, how often do you use this per week?



Reaching out to carers of friends and family with psychosis: A model for an online intervention to improve carer wellbeing and quality of life.

WEMWBS (Stewart-Brown et al., 2008)

Participant Number

Please read through the following statements and circle the number that best describes your thoughts and feelings over the last 2 weeks.

	Areas of Wellbeing	None of the time	Rarely	Some of the time	Often	All of the time
	I have been:					
1.	*feeling optimistic about the future*	1	2	3	4	5
2.	*feeling useful*	1	2	3	4	5
3.	*feeling relaxed*	1	2	3	4	5
4.	*feeling interested in other people*	1	2	3	4	5
5.	*having energy to spare*	1	2	3	4	5
6.	*dealing with problems well*	1	2	3	4	5
7.	*thinking clearly*	1	2	3	4	5
8.	*feeling good about myself*	1	2	3	4	5
9.	*feeling close to other people*	1	2	3	4	5
10.	*feeling confident*	1	2	3	4	5
11.	*able to make up my own mind about things*	1	2	3	4	5
12.	*feeling loved*	1	2	3	4	5
13.	*interested in new things*	1	2	3	4	5

14.	*feeling cheerful*	1	2	3	4	5
	Total score =					

HADS

The Adult Carer Quality of Life Questionnaire (AC-QoL)

How to Fill in the Questionnaire

This questionnaire asks you about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer. The questionnaire shouldn't take more than 10 minutes.

Please answer all questions as honestly as you can.

	Never	Some of the time	A lot of the time	Always
Support for Caring				
01. I have a good level of emotional support	☐	☐	☐	☐
02. My needs as a carer are considered by professionals	☐	☐	☐	☐
03. I am happy with the professional support that is provided to me	☐	☐	☐	☐
04. I feel able to get the help and information I need	☐	☐	☐	☐
05. I have all the practical support I need	☐	☐	☐	☐
Caring Choice				
06. I feel that my life is on hold because of caring	☐	☐	☐	☐
07. My social life has suffered because of caring	☐	☐	☐	☐
08. I feel I have less choice about my future due to caring	☐	☐	☐	☐
09. I feel I have no control over my own life	☐	☐	☐	☐
10. Caring stops me doing what I want to do	☐	☐	☐	☐
Caring Stress				
11. I feel depressed due to caring	☐	☐	☐	☐
12. I feel worn out as a result of caring	☐	☐	☐	☐
13. I am mentally exhausted by caring	☐	☐	☐	☐
14. I am physically exhausted by caring	☐	☐	☐	☐
15. I feel stressed as a result of caring	☐	☐	☐	☐

	Never	Some of the time	A lot of the time	Always
Money Matters				
16. I worry about going into debt	☐	☐	☐	☐
17. I feel satisfied with my financial situation	☐	☐	☐	☐
18. I am able to save for a rainy day	☐	☐	☐	☐
19. I worry about money	☐	☐	☐	☐
20. There is enough money in our house to pay for the things we need	☐	☐	☐	☐
Personal Growth				
21. I have become a more tolerant person through my caring role	☐	☐	☐	☐
22. Because of caring, I have learnt a lot about myself	☐	☐	☐	☐
23. Because of caring, I feel that I have grown as a person	☐	☐	☐	☐
24. I have experienced many positive things through caring	☐	☐	☐	☐
25. I feel that I have become a better person by caring	☐	☐	☐	☐
Sense of Value				
26. I feel valued by the person I am looking after	☐	☐	☐	☐
27. The person I look after respects me for what I do	☐	☐	☐	☐
28. The person I look after makes me feel good about myself	☐	☐	☐	☐
29. I get a lot from the person I am looking after	☐	☐	☐	☐
30. I have a good relationship with the person I am caring for	☐	☐	☐	☐
Ability to Care				
31. I am satisfied with my performance as a carer	☐	☐	☐	☐
32. I can take care of the needs of the person I am caring for	☐	☐	☐	☐
33. I feel I am able to make the life of the person I am looking after better	☐	☐	☐	☐
34. I can manage most situations with the person I care for	☐	☐	☐	☐
35. I am able to deal with a difficult situation	☐	☐	☐	☐
Carer Satisfaction				
36. Caring is important to me	☐	☐	☐	☐
37. I resent having to be a carer	☐	☐	☐	☐
38. I feel frustrated with the person I am caring for	☐	☐	☐	☐
39. I enjoy being a carer	☐	☐	☐	☐
40. I am satisfied with my life as a carer	☐	☐	☐	☐

Reaching Out to Carers of Friends and Family with Severe Mental Illness: A Model for an Online Intervention to Improve Carer Wellbeing and Quality of Life.

Name of Researcher: Amy Johnson

Name of Supervisor: Dr. Markku Wood

Diary of Online Support.

This is the weekly diary form for carers, family and friends of people with severe mental illness who are taking part in the study, 'Reaching Out to Carers of Friends and Family with Severe Mental Illness: A Model for an Online Intervention to Improve Carer Wellbeing and Quality of Life.' You have been asked to complete this weekly for up to 6 weeks before being invited to attend an interview.

The questions in this booklet cover some of the available online support for carers of someone with a severe mental illness. The support included in the questions consist of charity websites, online forums, online courses, iTunes U, and mobile phone apps. There are also spaces for you to include online support you have used that may not be included.

Information provided here will be used to develop a model of an online intervention aiming to increase wellbeing and quality of life of carers, family or friends of someone with a severe mental illness. If you have any questions completing this diary or about the project, please email me at amy.johnson@northumbria.ac.uk

Week 1

Participant Number

1. Have you used any online support in the last week? *(If you have answered 'yes' move onto Question 2. If you have answered 'no', please leave the rest of this week blank)*

Yes ☐ No ☐

2. Please tick if, in the last week, you have used any of the online support listed below.

The Carer Trust Website	☐
The Carer Trust online forum	☐
Carers UK Website	☐
Carers UK online forum	☐
The Mind Website	☐
Mind online forum (Elefriends)	☐
Rethink website	☐
The Royal College of Psychiatrists website	☐
Caring for people with psychosis and schizophrenia (FutureLearn Online Course)	☐
Caring with Confidence	☐
iTunes U	☐
Mobile Phone Apps	☐
Other	☐

If other, please state:

3. If you have used online support, please complete the table below.

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
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	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Week 2

Participant Number

1. Have you used any online support in the last week? *(If you have answered 'yes' move onto Question 2. If you have answered 'no', please leave the rest of this week blank)*

Yes ☐ No ☐

2. Please tick if, in the last week, you have used any of the online support listed below.

The Carer Trust Website	☐
The Carer Trust online forum	☐
Carers UK Website	☐
Carers UK online forum	☐
The Mind Website	☐
Mind online forum (Elefriends)	☐
Rethink website	☐
The Royal College of Psychiatrists	☐
Caring for people with psychosis and schizophrenia (FutureLearn Online Course)	☐
Caring with Confidence	☐
iTunes U	☐
Mobile Phone Apps	☐
Other	☐

If other, please state:

3. If you have used online support, please complete the table below.

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Week 3

Participant Number

1. Have you used any online support in the last week? *(If you have answered 'yes' move onto Question 2. If you have answered 'no', please leave the rest of this week blank)*

Yes ☐ No ☐

2. Please tick if, in the last week, you have used any of the online support listed below.

The Carer Trust Website	☐
The Carer Trust online forum	☐
Carers UK Website	☐
Carers UK online forum	☐
The Mind Website	☐
Mind online forum (Elefriends)	☐
Rethink website	☐
The Royal College of Psychiatrists	☐
Caring for people with psychosis and schizophrenia (FutureLearn Online Course)	☐
Caring with Confidence	☐
iTunes U	☐
Mobile Phone Apps	☐
Other	☐

If other, please state:

3. If you have used online support, please complete the table below.

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
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	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Week 4

Participant Number

1. Have you used any online support in the last week? *(If you have answered 'yes' move onto Question 2. If you have answered 'no', please leave the rest of this week blank)*

Yes ☐ No ☐

2. Please tick if, in the last week, you have used any of the online support listed below.

The Carer Trust Website	☐
The Carer Trust online forum	☐
Carers UK Website	☐
Carers UK online forum	☐
The Mind Website	☐
Mind online forum (Elefriends)	☐
Rethink website	☐
The Royal College of Psychiatrists	☐
Caring for people with psychosis and schizophrenia (FutureLearn Online Course)	☐
Caring with Confidence	☐
iTunes U	☐
Mobile Phone Apps	☐
Other	☐

If other, please state:

_____

3. If you have used online support, please complete the table below.

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
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	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Name of Online Support accessed	How often did you access this within the last week? *Please Tick ✓*		How long did you spend on this within the last week? *Please Tick ✓*		What did you like about this?	What didn't you like about this?	Any other comments?
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	3-4 times		1-3 hours				
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	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Week 5

Participant Number

1. Have you used any online support in the last week? *(If you have answered 'yes' move onto Question 2. If you have answered 'no', please leave the rest of this week blank)*

Yes ☐ No ☐

2. Please tick if, in the last week, you have used any of the online support listed below.

The Carer Trust Website	☐
The Carer Trust online forum	☐
Carers UK Website	☐
Carers UK online forum	☐
The Mind Website	☐
Mind online forum (Elefriends)	☐
Rethink website	☐
The Royal College of Psychiatrists	☐
Caring for people with psychosis and schizophrenia (FutureLearn Online Course)	☐
Caring with Confidence	☐
iTunes U	☐
Mobile Phone Apps	☐
Other	☐

If other, please state:

_____

3. If you have used online support, please complete the table below.

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
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	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
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	3-4 times		1-3 hours				
	5+ times		4-6 hours				
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	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Week 6

Participant Number

1. Have you used any online support in the last week? *(If you have answered 'yes' move onto Question 2. If you have answered 'no', please leave the rest of this week blank)*

Yes ☐ No ☐

2. Please tick if, in the last week, you have used any of the online support listed below.

The Carer Trust Website	☐
The Carer Trust online forum	☐
Carers UK Website	☐
Carers UK online forum	☐
The Mind Website	☐
Mind online forum (Elefriends)	☐
Rethink website	☐
The Royal College of Psychiatrists	☐
Caring for people with psychosis and schizophrenia (FutureLearn Online Course)	☐
Caring with Confidence	☐
iTunes U	☐
Mobile Phone Apps	☐
Other	☐

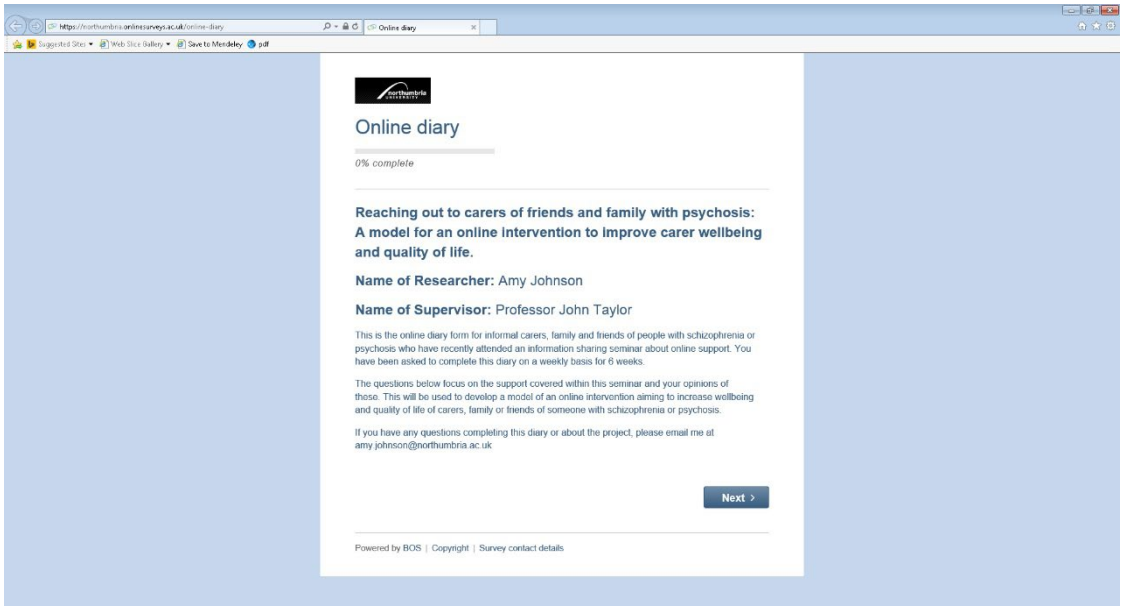
If other, please state:

3. If you have used online support, please complete the table below.

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Name of Online Support accessed	How often did you access this within the last week? *Please Tick* ✓		How long did you spend on this within the last week? *Please Tick* ✓		What did you like about this?	What didn't you like about this?	Any other comments?
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				
	1 -2 times		Less than 1 hour				
	3-4 times		1-3 hours				
	5+ times		4-6 hours				
			7+ hours				

Thank you for completing this diary.


Online diary
0% complete
Reaching out to carers of friends and family with psychosis: A model for an online intervention to improve carer wellbeing and quality of life.
Name of Researcher: Amy Johnson
Name of Supervisor: Professor John Taylor
This is the online diary form for informal carers, family and friends of people with schizophrenia or psychosis who have recently attended an information sharing seminar about online support. You have been asked to complete this diary on a weekly basis for 6 weeks.
The questions below focus on the support covered within this seminar and your opinions of these. This will be used to develop a model of an online intervention aiming to increase wellbeing and quality of life of carers, family or friends of someone with schizophrenia or psychosis.
If you have any questions completing this diary or about the project, please email me at amy.johnson@northumbria.ac.uk
Next ›
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Online diary
4% complete
Please enter you participation number in the box below. * Required
Please select which week * Required
Week 1
Week 2
Week 3
Week 4
Week 5
Week 6
‹ Previous
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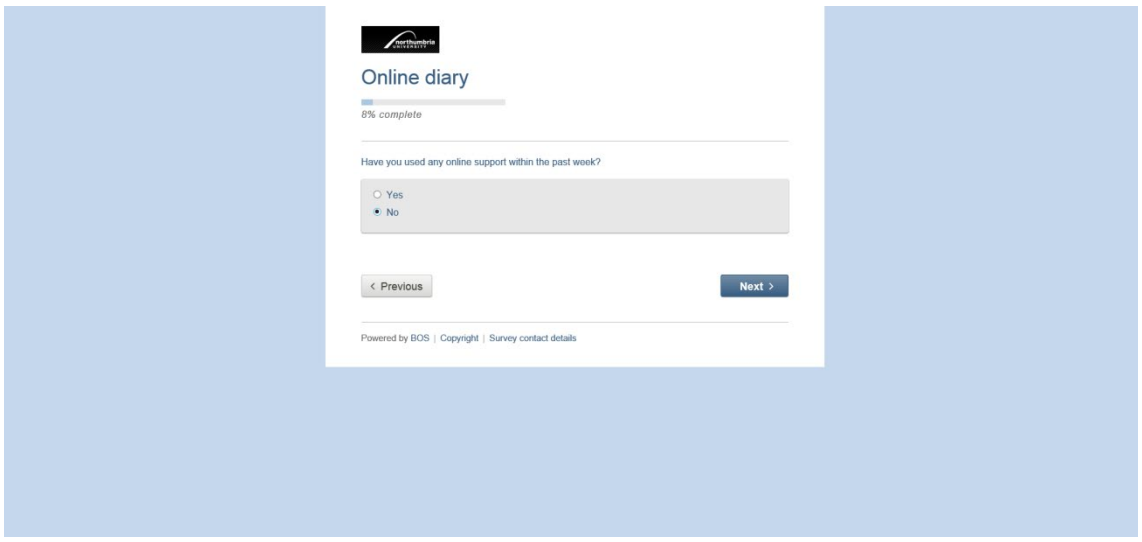
Online diary
8% complete
Have you used any online support within the past week?
Yes
No
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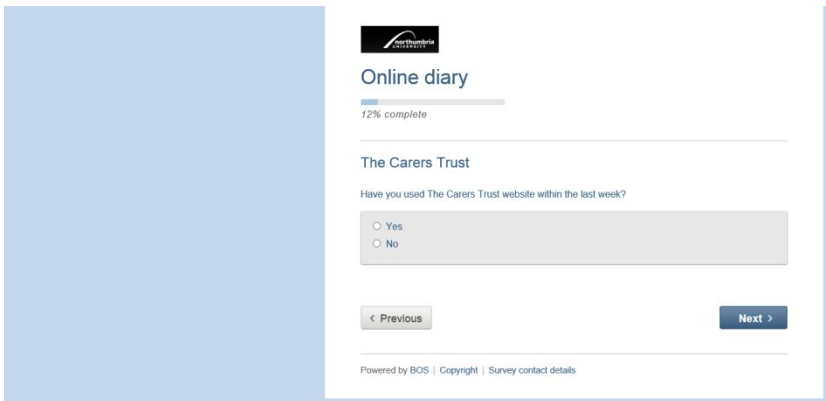

Online diary

12% complete

The Carers Trust

Have you used The Carers Trust website within the last week?

- Yes
- No

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Online diary

16% complete

The Carers Trust

This part of the survey uses a table of questions, view as separate questions instead?

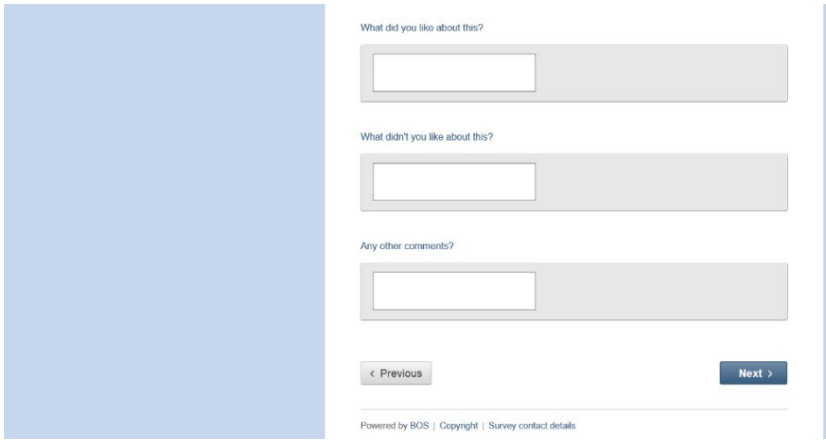
How often did you access The Carer Trust website in the last week?

	How often did you access this within the last week?			
	Did not access this resource	1 - 2 times	3 - 4 times	5+ times
The information on the website	○	○	○	○
The online form	○	○	○	○

This part of the survey uses a table of questions, view as separate questions instead?

In total, how long did you spend on the Carer Trust website within the last week?

	Did not access this resource	Less than 1 hour	1-3 hours	4-6 hours	7+ hours
The information on the website	○	○	○	○	○
The online forum	○	○	○	○	○



What did you like about this?

What didn't you like about this?

Any other comments?

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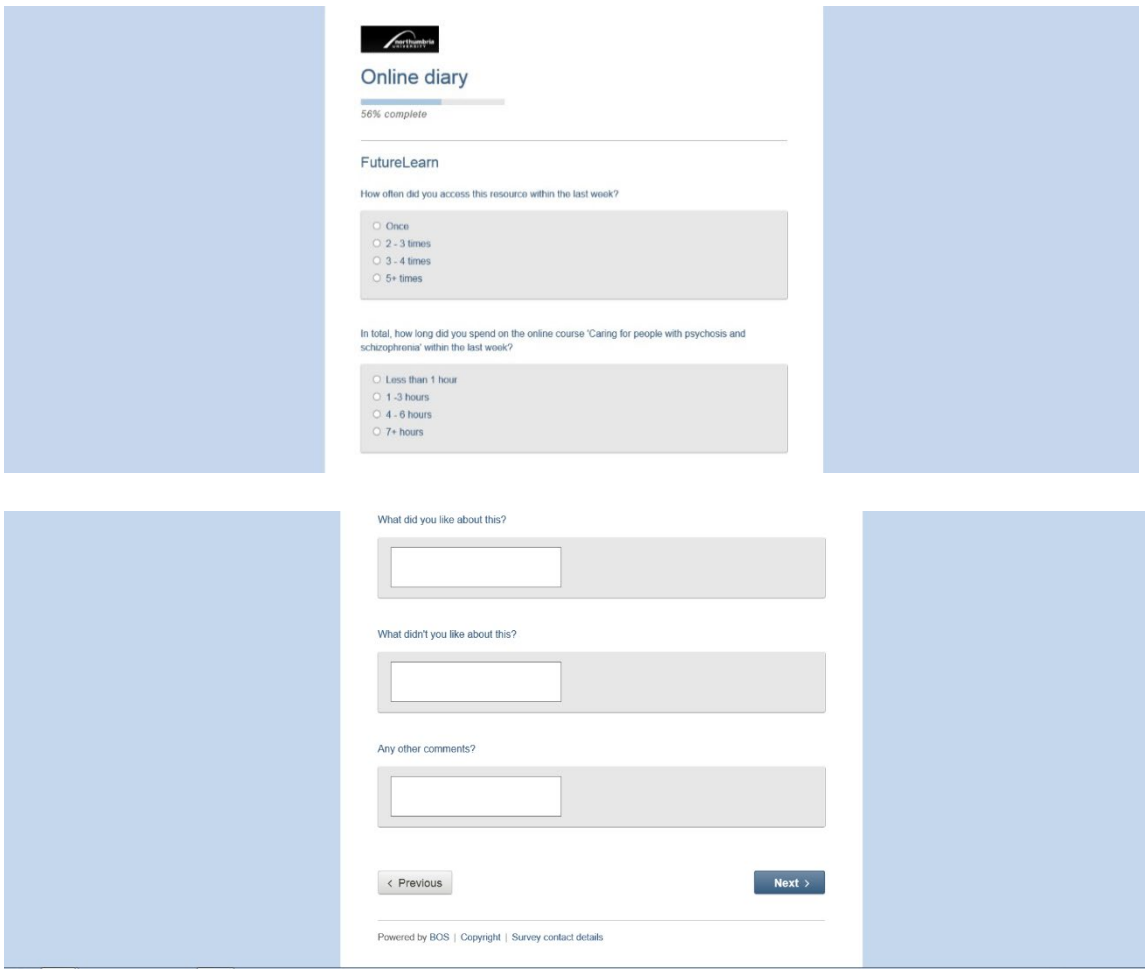

Online diary

56% complete

FutureLearn

How often did you access this resource within the last week?

- Once
- 2 - 3 times
- 3 - 4 times
- 5+ times

In total, how long did you spend on the online course 'Caring for people with psychosis and schizophrenia' within the last week?

- Less than 1 hour
- 1 -3 hours
- 4 - 6 hours
- 7+ hours

What did you like about this?

What didn't you like about this?

Any other comments?

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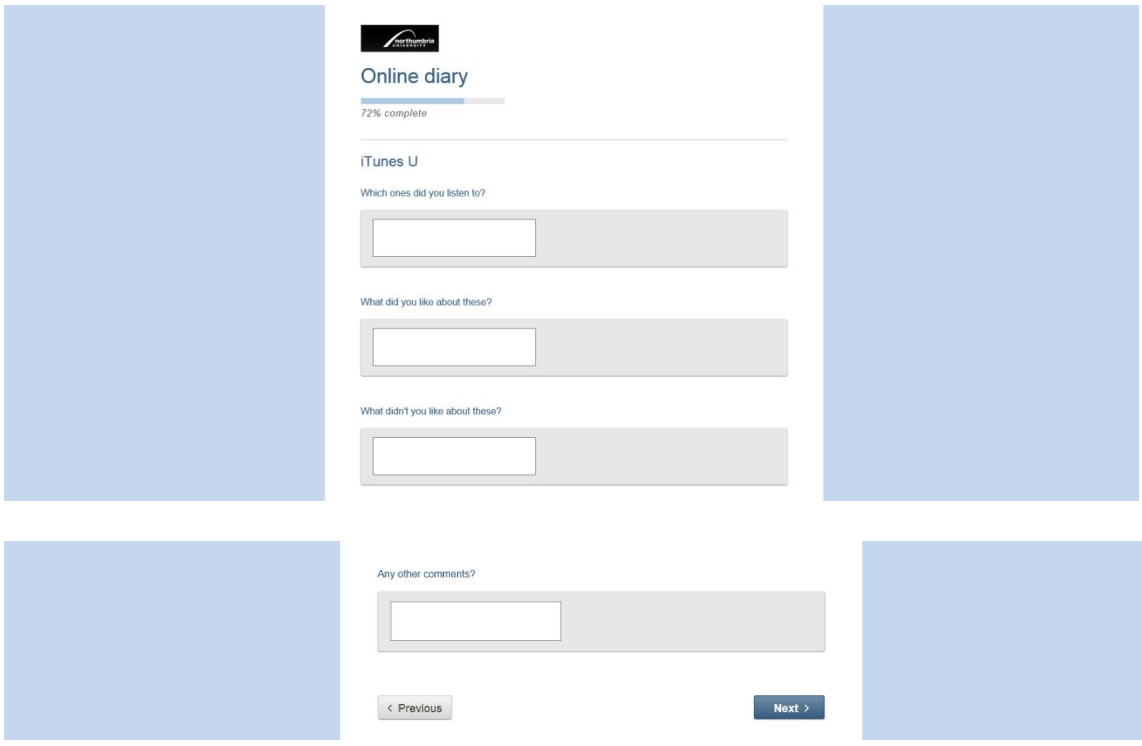

Online diary

72% complete

iTunes U

Which ones did you listen to?

What did you like about these?

What didn't you like about these?

Any other comments?

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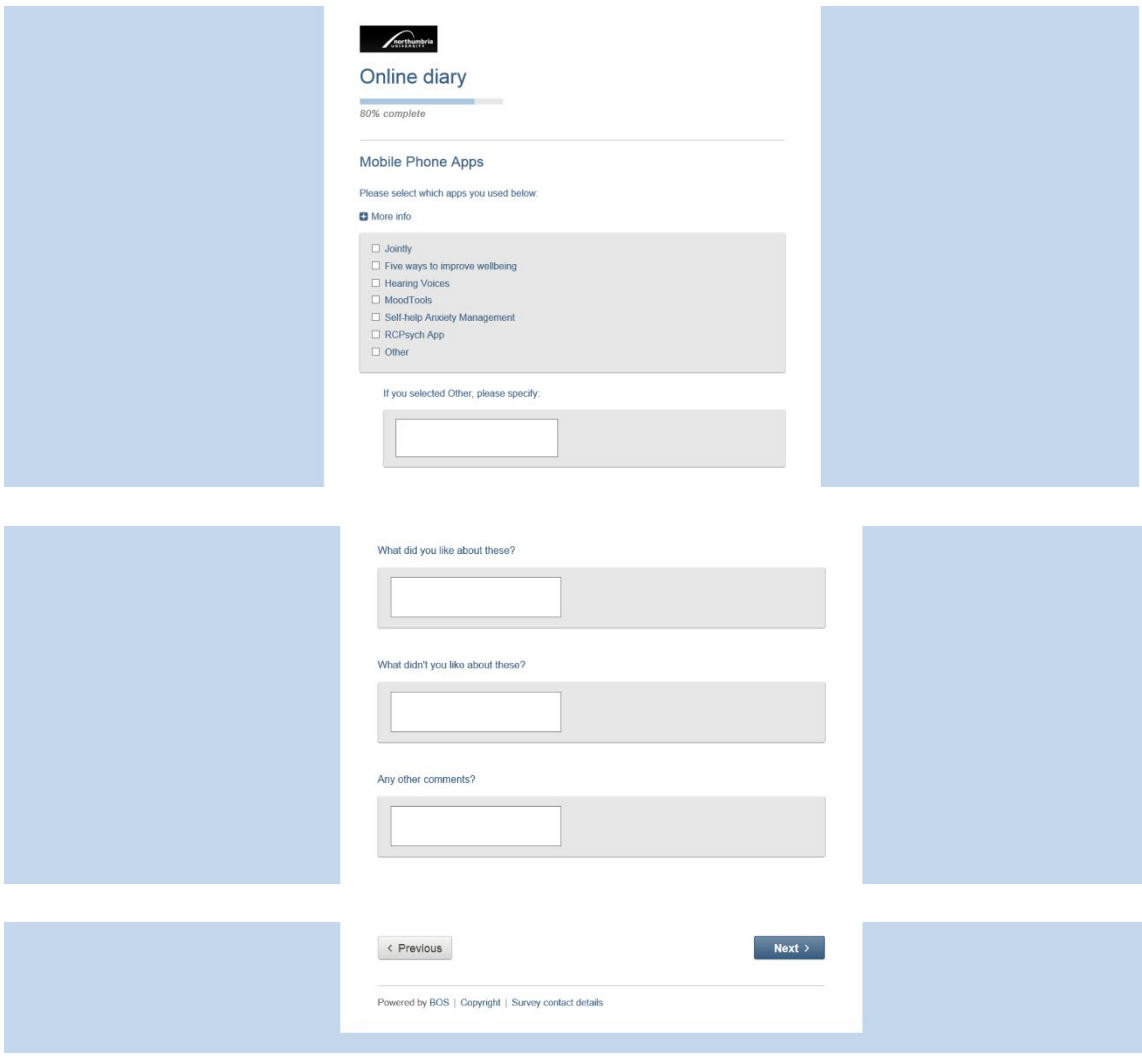
Online diary
80% complete
Mobile Phone Apps
Please select which apps you used below:
More info
Jointly
Five ways to improve wellbeing
Hearing Voices
MoodTools
Self-help Anxiety Management
RCPsych App
Other
If you selected Other, please specify:
What did you like about these?
What didn't you like about these?
Any other comments?
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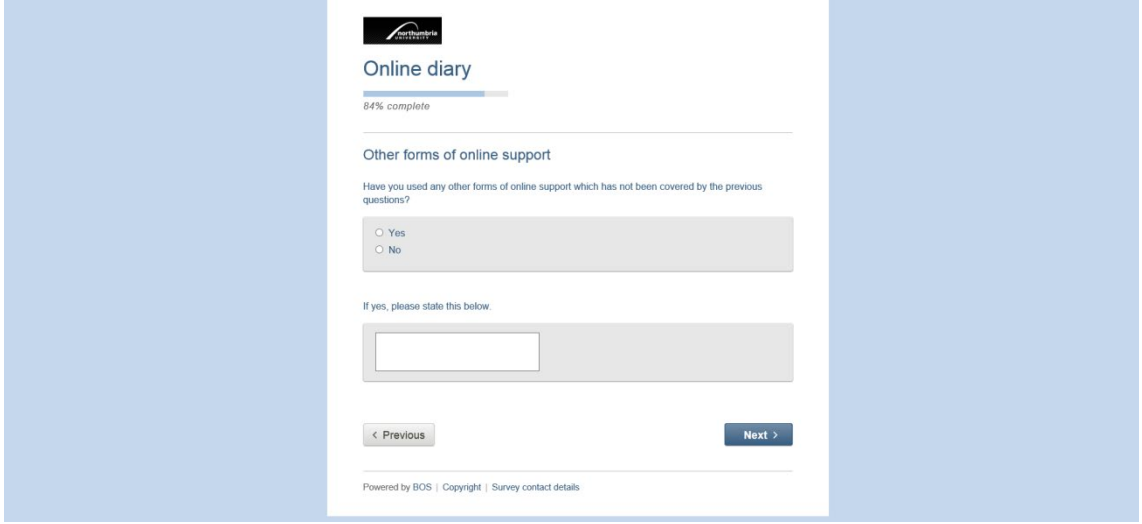
Online diary
84% complete
Other forms of online support
Have you used any other forms of online support which has not been covered by the previous questions?
Yes
No
If yes, please state this below.
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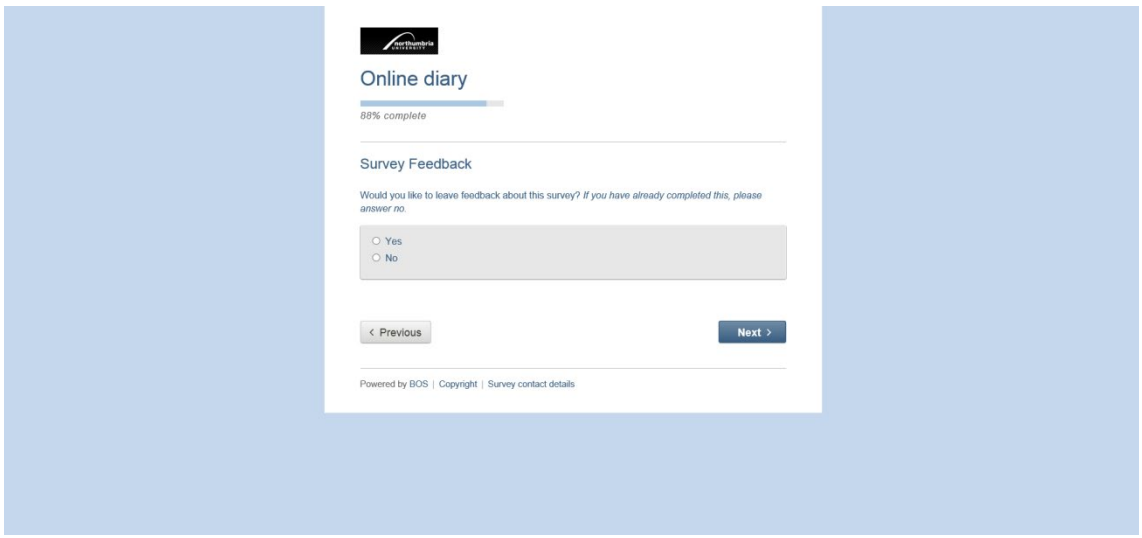
Online diary
88% complete
Survey Feedback
Would you like to leave feedback about this survey? If you have already completed this, please answer no.
Yes
No
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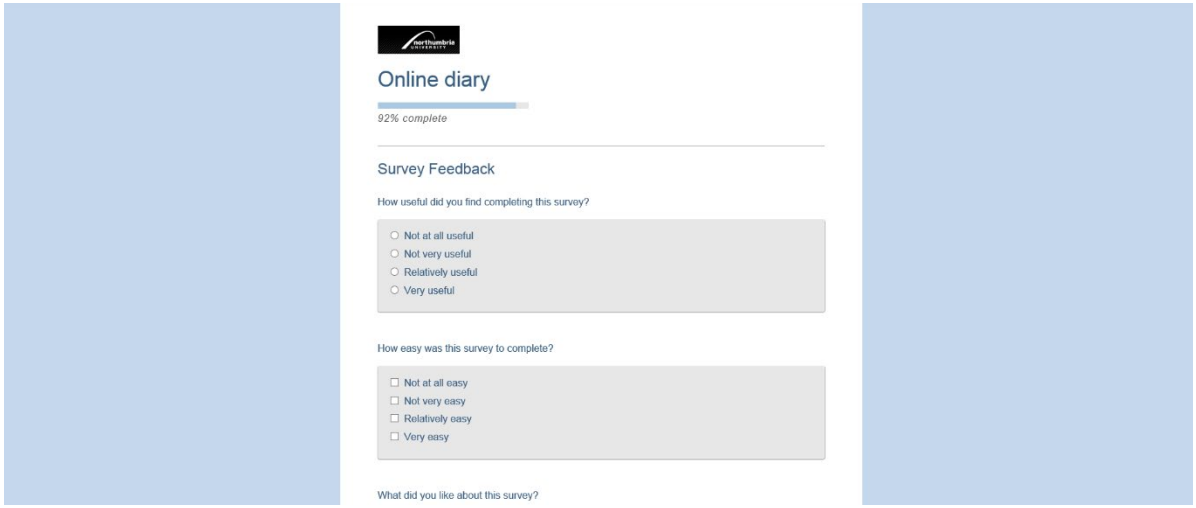
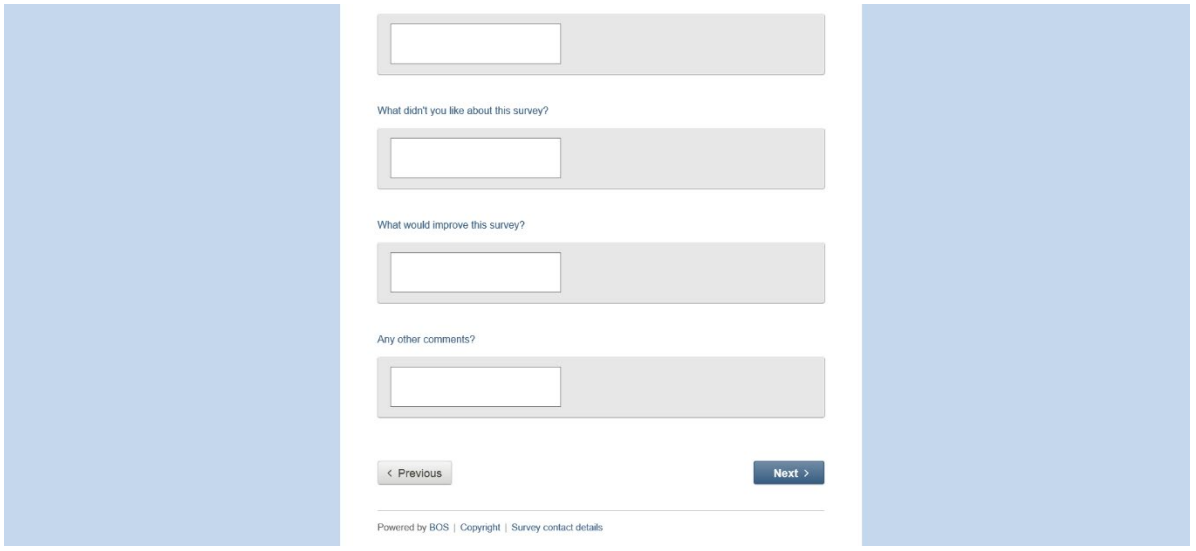

Online diary
92% complete
Survey Feedback
How useful did you find completing this survey?
Not at all useful
Not very useful
Relatively useful
Very useful
How easy was this survey to complete?
Not at all easy
Not very easy
Relatively easy
Very easy
What did you like about this survey?


What didn't you like about this survey?
What would improve this survey?
Any other comments?
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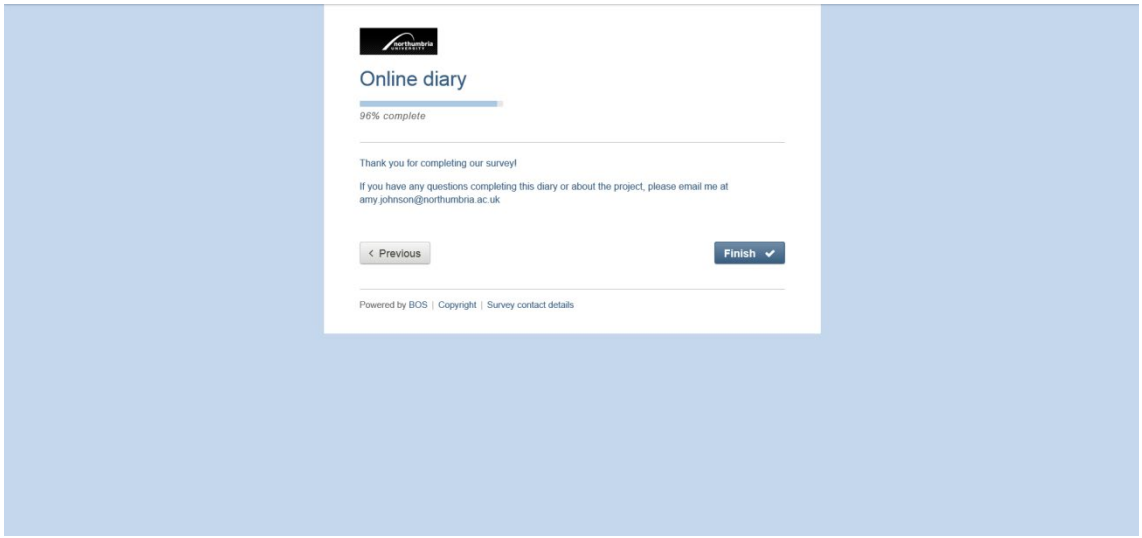
Online diary
96% complete
Thank you for completing our survey!
If you have any questions completing this diary or about the project, please email me at amy.johnson@northumbria.ac.uk
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Finish
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Reaching Out to Carers of Friends and Family with Severe Mental Illness: A Model for an Online Intervention to Improve Carer Wellbeing and Quality of Life.

Name of Researcher: Amy Johnson

Name of Supervisor: Dr Markku Wood

Carer Interview Information

Participant Number

I would like to attend a focus group or individual interview to share my opinions of the online interventions. ☐

How many online or eHealth interventions did you try?

None ☐

A few ☐

All of them ☐

Are you currently receiving support to help you within your role?

Yes ☐ No ☐

If yes, please specify:

Over the past 6 weeks, how well has your friend or relative been?

Not at all | Not very | Quite | Very

Which type of interview would you like to attend?

Telephone Interview ☐

Skype Interview ☐

When is best for you to attend the interview (please tick)?

	Morning	**Afternoon**	**Evening**
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Reaching out to carers of friends and family with a severe mental illness: A model for an online intervention to improve carer wellbeing and quality of life.

Topic Guide – Focus Groups or Individual Interviews (Carer)

Introduction

Recap what participant has been doing for the last 6 weeks. Remind about confidentiality and the ability to take breaks or leave the discussion is the participant feels that they need to.

General Information

- Can you please tell us your name and how long you have been a carer?

Evaluating the online interventions

- What is your opinion about online support or interventions available to carers, family and friends of a severe mental illness?
- Do you experience any problems using or accessing these?
- What effect, if any, do you feel online interventions have on your wellbeing?
    - What parts were helpful for your wellbeing?
    - What parts were unhelpful for your wellbeing?
- What effect, if any, do you feel online interventions have on your quality of life?
    - What parts were helpful for your quality of life?
    - What parts were unhelpful for your quality of life?

Recommendations for the new online model.

- What would you like to see included in a new online intervention aiming to improve the wellbeing of carers, family and friends of someone with a severe mental illness, such as carer of people with schizophrenia, psychosis, bipolar disorder or personality disorders?
- What would you like to see included in a new online intervention aiming to improve the quality of life of carers, family and friends of someone with a severe mental illness?
- Is there anything in particular (such as any issues) that should be taken into account when making this online intervention?
- Is there anything that hasn't been included within online support which you think could be helpful for your wellbeing and quality of life?
- Is there anything you would like to add?

Thank you for your time.

Reaching out to carers of friends and family with a severe mental illness: A model for an online intervention to improve carer wellbeing and quality of life.

Topic Guide – Focus Groups or Individual Interviews (Carer)

Introduction

Recap what participant has been doing for the last 6 weeks. Remind about confidentiality and the ability to take breaks or leave the discussion if the participant feels that they need to.

General Information

- Can you please tell us your name and how long you have been a carer?

Evaluating the online interventions

- What factors prevent you from using online interventions or support to help you within your caring role?
- How could these be resolved?

Recommendations for the new online model.

- What would you like to see included in a new intervention aiming to improve the wellbeing of carers, family and friends of someone with a severe mental illness, such as carer of people with schizophrenia, psychosis, bipolar disorder or personality disorders?
- What would you like to see included in a new intervention aiming to improve the quality of life of carers, family and friends of someone with a severe mental illness?
- Is there anything in particular (such as any issues) that should be taken into account when making this online intervention?
- Is there anything that hasn't been included in these interventions which you think could be helpful for your wellbeing and quality of life?
- Is there anything you would like to add?

Thank you for your time.

Reaching Out to Carers of Friends and Family with Severe Mental Illness: A Model for an Online Intervention to Improve Carer Wellbeing and Quality of Life.

Professional Baseline Information

Participant Number

Gender: _____

Age: _____ Years

Ethnicity: _____

Highest level of education

Primary Education or less	☐
Secondary Education	☐
Higher education	☐
Other	☐

What is your job role?

_____

What are your duties with regards to carers?

_____

_____

_____

Do you recommend any internet-based support to carers who you work with?

Yes ☐ No ☐

If so, what do you recommend?

Reaching out to carers of friends and family with severe mental illness: A model for an online intervention to improve carer wellbeing and quality of life.

Topic Guide – Focus Groups or Individual Interviews

Introduction

Remind about confidentiality and the ability to take breaks or leave the discussion is the participant feels that they need to.

General Information

- Can you please tell us how long you have worked with informal carers?
- What does your role involve?

Evaluating the online interventions

- What were your opinions about online interventions or support available for carers, families and friends of people with severe mental illness, such as carers of people with schizophrenia, psychosis, bipolar disorder or personality disorders?
- Do you think carers will experience any problems using these?
- What effects do you think that online interventions or support will have on carer wellbeing?
    - What parts did you think were helpful?
    - What parts did you think were unhelpful?
- What effects do you think that online interventions or support will have on carer quality of life?
    - What parts did you think were helpful?
    - What parts did you think were unhelpful?

Recommendations for the new online model.

- What would you like to see included in a new online intervention aiming to improve the wellbeing of carers, family and friends of someone with a severe mental illness?
- What would you like to see included in a new online intervention aiming to improve the quality of life of carers, family and friends of someone with a severe mental illness?
- Is there anything in particular (such as any issues) that should be taken into account when making an online intervention?

- Is there anything that hasn't been included within online interventions which you think could be helpful for carer wellbeing and quality of life?

Thank you for your time.

Appendix 4 : QCA

QCA Calibration

QCA incorporates the use of truth tables to identify causal conditions relating to an outcome. As outlined in chapter three, the change between the outcome measures at baseline and 6-weeks follow-up were calculated and were converted into crisp-set values with '0' indicating a negative or decreased change and '1' illustrating a positive or increased change in scores. In contrast, anxiety and depression questionnaires were calibrated as '1' indicating no change or reduced scores and '0' regarding increased scores. The calibration scores for the outcome measures are outlined in the below table:

Table A.1. The calibration of the outcome measures (or clusters) included in the QCA.

WEMWBS	1	Positive change in support for caring subscale
	0	Negative or no change in support for caring subscale
HADS (depression change)	1	Negative or no change in depression subscale
	0	Positive change in depression subscale
HADS (anxiety change)	1	Negative or no change in anxiety subscale
	0	Positive change in anxiety subscale
AC_QoL total change	1	Positive change in total QoL subscale
	0	Negative or no change in total QoL subscale
AC_QoL support for caring	1	Positive change in support for caring subscale
	0	Negative or no change in support for caring subscale
AC_QoL caring choice	1	Positive change in caring choice subscale
	0	Negative or no change in caring choice subscale
AC_QoL caring stress	1	Positive change in caring stress subscale
	0	Negative or no change in caring stress subscale
AC_QoL money matters	1	Positive change in money matters subscale
	0	Negative or no change in money matters subscale
AC_QoL personal growth	1	Positive change in personal growth subscale
	0	Negative or no change in personal growth subscale
AC_QoL sense of value	1	Positive change in sense of value subscale
	0	Negative or no change in sense of value subscale
AC_QoL ability to care	1	Positive change in ability to care subscale
	0	Negative or no change in ability to care subscale
AC_QoL carer satisfaction	1	Positive change in carer satisfaction subscale
	0	Negative or no change in carer satisfaction subscale

The positive and negative change of the outcome measures were selected to highlight the specific impact of web-based resources on carer health. The below sections present the

QCA incorporating the week of highest access of web-based resources over the 6-week period and weekly web-based support use. The resultant prime implicants are highlighted in grey. The use of upper case in the below findings indicate presence of a positive change in the causal conditions towards the outcome.

QCA incorporating the use of web-based resources over the 6-week period

The below table outlines the calibrations of the causal conditions included within the first QCA. The conditions were calculated for each carer as reported within the 6-week diaries, for instance total weeks accessing web-based support. The calibration of these causal conditions into csp-set values was determined by identification of the median values or "natural breaks in the data", otherwise referred to as the point of ambiguity (Schneider & Wageman, 2012). For instance, the point of ambiguity for total number of web-based resources accessed was identified as 6 resources. Thus, data points below 6 were calibrated as 0, indicating no to low amount of web-based support accessed. In contrast, scores over 6 were calibrated as 1, denoting moderate to high amount of resources accessed over the 6-week period.

Table A.2 The calibration of the causal conditions relating to web-based support usage over the 6-week period.

Total weeks of web-based support use	1	Moderate to high web-based support use
	0	No to low web-based support use
Total number of web-based resources accessed	1	Moderate to high amount of web-based support accessed
	0	No to low amount of web-based support accessed
Total number of times web-based resources were accessed	1	Moderate to high amount of times accessing web-based resources
	0	No to low amount of times accessing web-based resources
Total amount of time spent on web-based resources	1	Moderate to high amount of time spent on web-based resources
	0	No to low amount of time spent on web-based resources

Having outlined the calibration of causal conditions, the raw analysis is presented below.

Change in Depression Scores:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	HADSD Change
Brian	0	0	0	0	0
Eddie	0	0	0	0	0
Penny	0	0	1	0	0
Stella	1	1	1	1	0
Heather	0	0	0	0	1
Lynn	1	0	0	0	1
Maria	1	0	1	0	1
Rosa	1	1	1	1	1

There were no prime implicants associated with a change in depression score.

Change in Anxiety scores:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	HADSA Change
Maria	1	0	1	0	0
Stella	1	1	1	1	0
Brian	0	0	0	0	1
Eddie	0	0	0	0	1
Heather	0	0	0	0	1
Penny	0	0	1	0	1
Lynn	1	0	0	0	1
Rosa	1	1	1	1	1

Improvement in anxiety: TOTAL WEEKS OF ONLINE SUPPORT USE * TOTAL NUMBER OF TIMES RESOURCES ARE ACCESSED

Change in Total QoL:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	QoL Total Change
Brian	0	0	0	0	0
Heather	0	0	0	0	0
Lynn	1	0	0	0	0
Eddie	0	0	0	0	1
Penny	0	0	1	0	1
Maria	1	0	1	0	1
Stella	1	1	1	1	1
Rosa	1	1	1	1	1

No difference or reduction in QoL: total number of resources accessed * total number of times resources were accessed * total amount of time spent on online resources.

Change in Support for Caring:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	QoL SfC Change
Brian	0	0	0	0	0
Eddie	0	0	0	0	0
Penny	0	0	1	0	0
Stella	1	1	1	1	0
Rosa	1	1	1	1	0
Heather	0	0	0	0	1
Lyn	1	0	0	0	1
Maria	1	0	1	0	1

Increased feelings of Support for Caring: total number of resources accessed * total time spent on resources

Change in Caring Choice:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	QoL CCh Change
Penny	0	0	1	0	0
Lynn	1	0	0	0	0
Maria	1	0	1	0	0
Stella	1	1	1	1	0
Rosa	1	1	1	1	0
Brian	0	0	0	0	1
Eddie	0	0	0	0	1
Heather	0	0	0	0	1

Increased Caring Choice: total weeks online support access * total number of resources accessed * total times accessed * total time spent on online resources

Change in Money Matters:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	QoL MM Change
Brian	0	0	0	0	0
Eddie	0	0	0	0	0
Lynn	1	0	0	0	0
Maria	1	0	1	0	0
Heather	0	0	0	0	1
Penny	0	0	1	0	1
Stella	1	1	1	1	1
Maria	1	1	1	1	1

No Change or Negative change in Money Matters: total number of resources accessed * total time spent on online resources

Change in Personal Growth:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	QoL PG Change
Lynn	1	0	0	0	0
Maria	1	0	1	0	0
Stella	1	1	1	1	0
Rosa	1	1	1	1	0
Brian	0	0	0	0	1
Eddie	0	0	0	0	1
Heather	0	0	0	0	1
Penny	0	0	1	0	1

No Change/Reduction in Personal Growth: TOTAL WEEKS ACCESSING ONLINE SUPPORT.

Increase in Personal Growth: total weeks accessing online support * total number of resources accessed * total time spent on online resources.

Change in Sense of Value:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	QoL SoV Change
Penny	0	0	1	0	0
Stella	1	1	1	1	0
Brian	0	0	0	0	1
Eddie	0	0	0	0	1
Heather	0	0	0	0	1
Lynn	1	0	0	0	1
Maria	1	0	1	0	1
Rosa	1	1	1	1	1

Sense of Value: number of times resources were accessed

Change in Ability to Care:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	QoL AtC Change
Brian	0	0	0	0	0
Eddie	0	0	0	0	0
Heather	0	0	0	0	0
Lynn	1	0	0	0	0
Rosa	1	1	1	1	0
Penny	0	0	1	0	1
Maria	1	0	1	0	1
Stella	1	1	1	1	1

Increase in Ability to Care: TOTAL NUMBER OF TIMES RESOURCES WERE ACCESSED

Change in Carer Satisfaction:

Ppt Number	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	QoL CSat Change
23	0	0	0	0	0
19	1	0	0	0	0
2	1	1	1	1	0
24	0	0	0	0	1
7	0	0	0	0	1
17	0	0	1	0	1
21	1	0	1	0	1
14	1	1	1	1	1

There were no prime implications associated with a change in carer satisfaction.

Change in Wellbeing:

Participant	Total weeks access	Total number of resources accessed	Total Number of Times Accessed	Total Time Spent on Resources	WEMWEBS Change
Maria	1	0	1	0	0
Stella	1	1	1	1	0
Brian	0	0	0	0	1
Eddie	0	0	0	0	1
Heather	0	0	0	0	1
Penny	0	0	1	0	1
Lynn	1	0	0	0	1
Rosa	1	1	1	1	1

No change or reduction in wellbeing: TOTAL WEEKS ACCESSING ONLINE SUPPORT * TOTAL NUMBER OF TIMES RESOURCES WERE ACCESSED.

QCA incorporating the week of highest access of web-based support.

The below table presents the calibrated causal conditions identified from the baseline questionnaire and including week three as the highest access of web-based support use. Calibrations were determined by responses on the carer baseline questionnaire, which were presented as csp-set options. The exceptions to this was care recipient health and hours of care provided per week where csp-set conditions were determined by consideration of raw data and location of the point of ambiguity.

Table A.3 Calibration of the causal conditions identified from demographic factors.

Carer occupation	1	Employed
	0	Unemployed/retired
Carer relationship to care recipient	1	Parent carer
	0	Spousal carer
Living arrangement	1	Live with the care recipient
	0	Does not live with the care recipient
Care recipient health at baseline	1	Unwell
	0	Well
Hours of care provided per week	1	Over 15 hours
	0	Under 15 hours
Receipt of support	1	Receiving support at baseline
	0	No support at baseline
Previous use of web-based resources	1	Yes
	0	No
Use of web-based resources at week three	1	Use of web-based resources
	0	No use of web-based resources

The prime implicants indicative of the outcome measures are outlined below.

Change in Depression:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	HADSD Change
Rosa	1	0	1	1	0	0	1	1	0
Brian	1	1	0	1	1	1	0	0	0
Lynn	2	0	1	1	0	1	0	0	0
Heather	2	1	1	0	1	0	0	0	0
Maria	1	1	0	0	1	0	1	1	1
Stella	1	1	1	1	0	0	1	1	1
Penny	1	1	1	1	1	0	0	1	1
Eddie	2	0	1	1	0	0	1	0	1

No Change or Reduction in Depression: carer support

Change in Anxiety:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	HADSA Change
Penny	1	1	1	1	1	0	0	1	0
Heather	2	1	1	0	1	0	0	0	0
Rosa	1	0	1	1	0	0	1	1	1
Maria	1	1	0	0	1	0	1	1	1
Brian	1	1	0	1	1	1	0	0	1
Stella	1	1	1	1	0	0	1	1	1
Eddie	2	0	1	1	0	0	1	0	1
Lynn	2	0	1	1	0	1	0	0	1

Increased Anxiety: LIVING ARRANGEMENTS * CARER RELATIONSHIP * CARE HOURS PER WEEK * carer support * net support

Change in Total QoL:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	QoL Total Change
Rosa	1	0	1	1	0	0	1	1	0
Brian	1	1	0	1	1	1	0	0	0
Eddie	2	0	1	1	0	0	1	0	0
Maria	1	1	0	0	1	0	1	1	1
Stella	1	1	1	1	0	0	1	1	1
Penny	1	1	1	1	1	0	0	1	1
Lynn	2	0	1	1	0	1	0	0	1
Heather	2	1	1	0	1	0	0	0	1

Reduction/No change in QoL: CARE RECIPIENT HEALTH

Change in Support for Caring:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	QoL SfC Change
Rosa	1	0	1	1	0	0	1	1	0
Maria	1	1	0	0	1	0	1	1	0
Stella	1	1	1	1	0	0	1	1	0
Lynn	2	0	1	1	0	1	0	0	0
Heather	2	1	1	0	1	0	0	0	0
Brian	1	1	0	1	1	1	0	0	1
Penny	1	1	1	1	1	0	0	1	1
Eddie	2	0	1	1	0	0	1	0	1

Support for Caring: CARE RECIPIENT HEALTH

Change in Caring Choice:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	QoL CCh Change
Stella	1	1	1	1	0	0	1	1	0
Penny	1	1	1	1	1	0	0	1	0
Eddie	2	0	1	1	0	0	1	0	0
Lynn	2	0	1	1	0	1	0	0	0
Heather	2	1	1	0	1	0	0	0	0
Rosa	1	0	1	1	0	0	1	1	1
Maria	1	1	0	0	1	0	1	1	1
Brian	1	1	0	1	1	1	0	0	1

Decreased or No Change in Caring Choice: CARER RELATIONSHIP

Increased Caring Choice: OCCUPATION

Change in Money Matters:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	QoL MM Change
Rosa	1	0	1	1	0	0	1	1	0
Maria	1	1	0	0	1	0	1	1	0
Penny	1	1	1	1	1	0	0	1	0
Eddie	2	0	1	1	0	0	1	0	0
Brian	1	1	0	1	1	1	0	0	1
Stella	1	1	1	1	0	0	1	1	1
Lynn	2	0	1	1	0	1	0	0	1
Heather	2	1	1	0	1	0	0	0	1

Money Matters: carer support

Change in Personal Growth:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	QoL PG Change
Penny	1	1	1	1	1	0	0	1	0
Eddie	2	0	1	1	0	0	1	0	0
Lynn	2	0	1	1	0	1	0	0	0
Heather	2	1	1	0	1	0	0	0	0
Rosa	1	0	1	1	0	0	1	1	1
Maria	1	1	0	0	1	0	1	1	1
Brian	1	1	0	1	1	1	0	0	1
Stella	1	1	1	1	0	0	1	1	1

Reduction in Personal Growth: CARER RELATIONSHIP

Increased Personal Growth: OCCUPATION

Sense of Value:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	QoL SoV Change
Stella	1	1	1	1	0	0	1	1	0
Lynn	2	0	1	1	0	1	0	0	0
Rosa	1	0	1	1	0	0	1	1	1
Maria	1	1	0	0	1	0	1	1	1
Brian	1	1	0	1	1	1	0	0	1
Penny	1	1	1	1	1	0	0	1	1
Eddie	2	0	1	1	0	0	1	0	1
Heather	2	1	1	0	1	0	0	0	1

Decreased Sense of Value: CARER RELATIONSHIP * CARE RECIPIENT HEALTH * care hours per week

Change in Ability to Care:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	QoL AtC Change
Rosa	1	0	1	1	0	0	1	1	0
Maria	1	1	0	0	1	0	1	1	0
Brian	1	1	0	1	1	1	0	0	0
Penny	1	1	1	1	1	0	0	1	0
Heather	2	1	1	0	1	0	0	0	0
Stella	1	1	1	1	0	0	1	1	1
Eddie	2	0	1	1	0	0	1	0	1
Lynn	2	0	1	1	0	1	0	0	1

Increase in Ability to Care: CARER RELATIONSHIP TO CARE RECIPIENT * CARE RECIPIENT HEALTH * care hours per week

Change in Carer Satisfaction:

Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	QoL CSat Change
Rosa	1	0	1	1	0	0	1	1	0
Penny	1	1	1	1	1	0	0	1	0
Lynn	2	0	1	1	0	1	0	0	0
Maria	1	1	0	0	1	0	1	1	1
Brian	1	1	0	1	1	1	0	0	1
Stella	1	1	1	1	0	0	1	1	1
Eddie	2	0	1	1	0	0	1	0	1
Heather	2	1	1	0	1	0	0	0	1

No difference or reduced carer satisfaction: CARER RELATIONSHIP * CARE RECIPIENT HEALTH

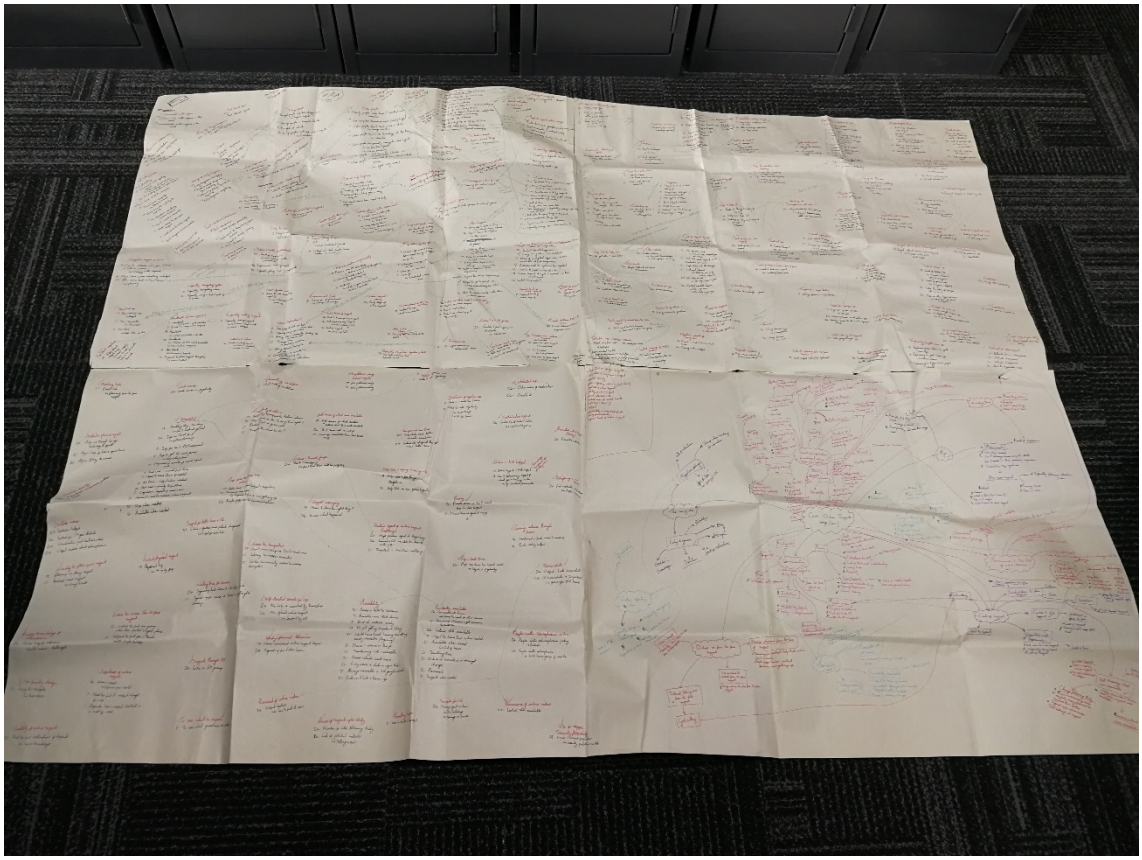
Change in Carer Wellbeing:

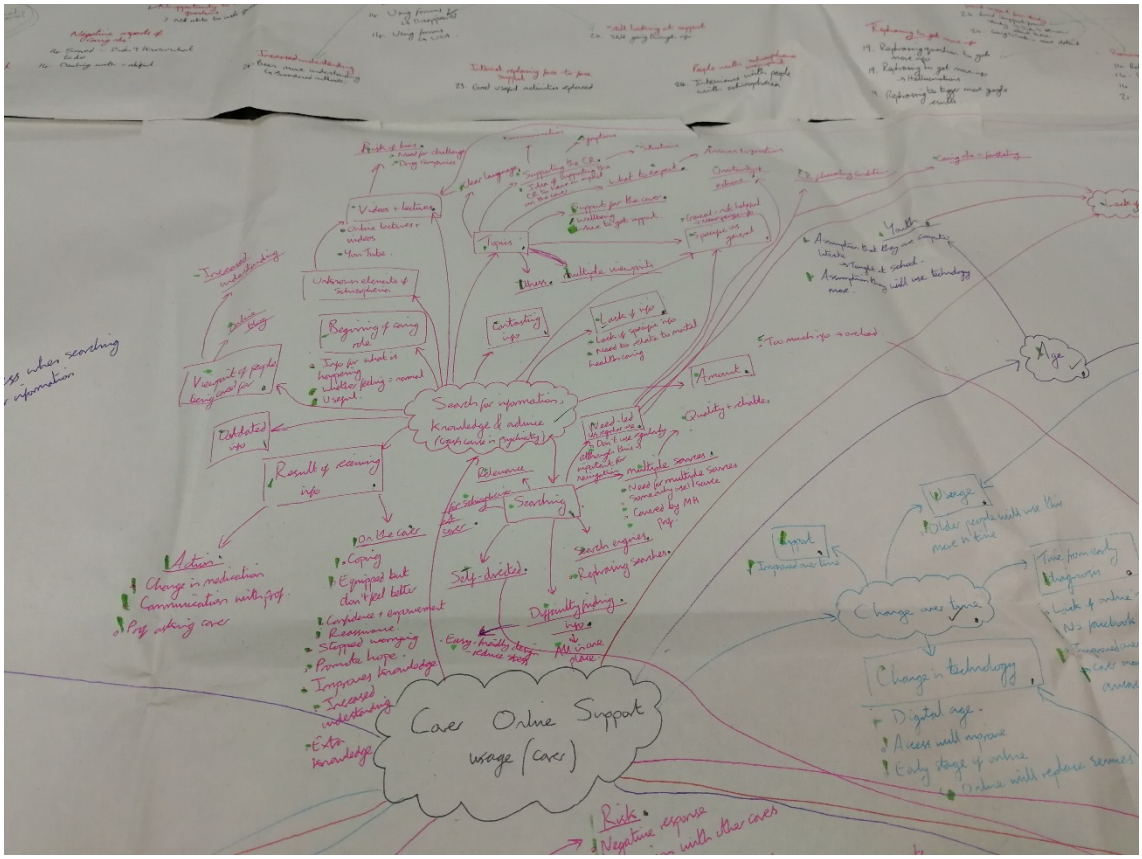
Participant	Occupation	Living Arr.	Carer Reln.	HealthCR	Care Hours per week	Carer Support	Net Support	Week 3 usage	WEMWEBS Change
Eddie	2	0	1	1	0	0	1	0	0
Lynn	2	0	1	1	0	1	0	0	0
Rosa	1	0	1	1	0	0	1	1	1
Maria	1	1	0	0	1	0	1	1	1
Brian	1	1	0	1	1	1	0	0	1
Stella	1	1	1	1	0	0	1	1	1
Penny	1	1	1	1	1	0	0	1	1
Heather	2	1	1	0	1	0	0	0	1

Reduced or no change in wellbeing: occupation * living arrangements * CARER RELATIONSHIP * CARE RECIPIENT HEALTH * care hours per week * week 3 online usage

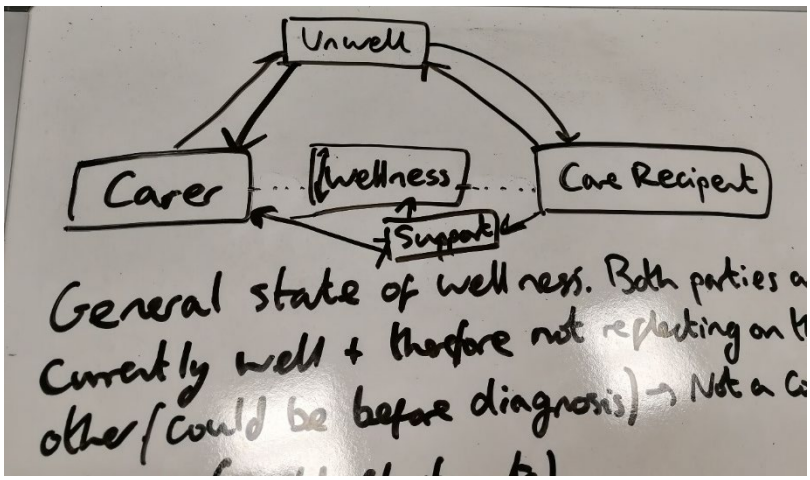
Appendix 5: Overview of analysis and reflective diary.

Development of themes

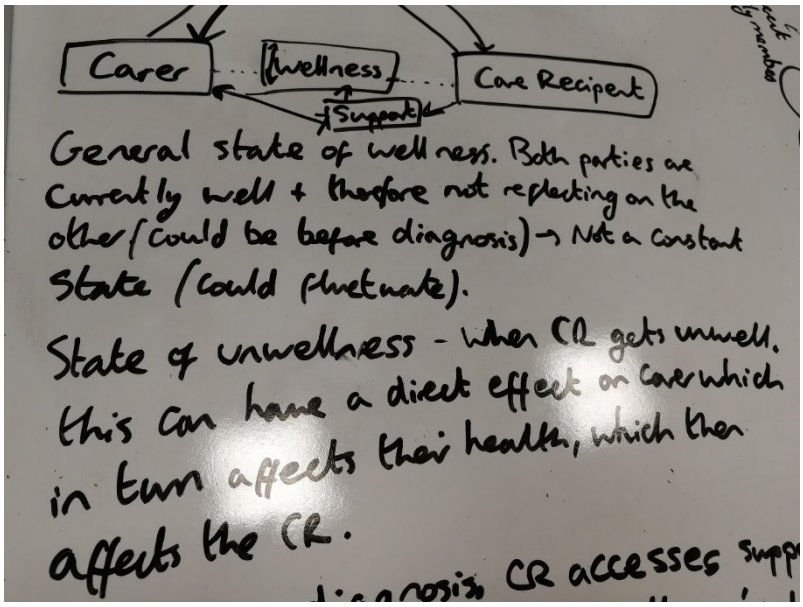




Development of further consideration founded on qualitative data.



General state of wellness. Both parties a
Currently well + therefore not reflecting on t
other (could be before diagnosis) → Not a c



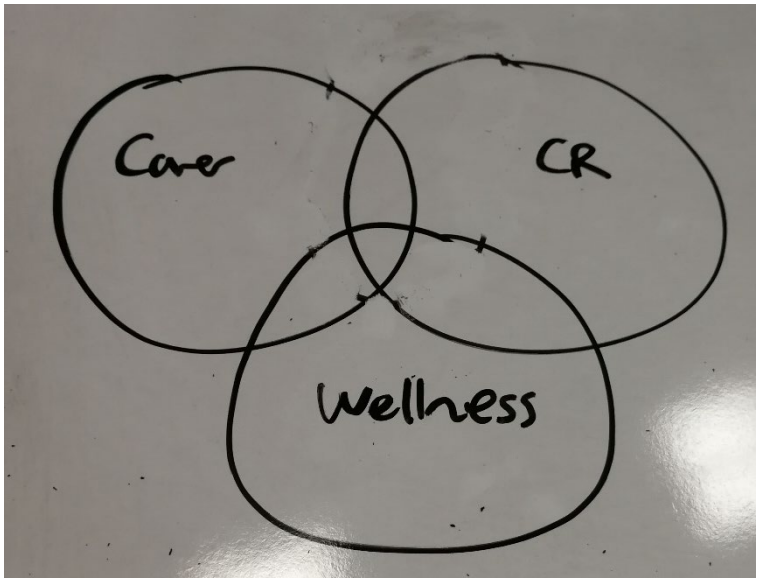
General state of wellness. Both parties are
Currently well + therefore not reflecting on the
other (could be before diagnosis) → Not a constant
State (could fluctuate).

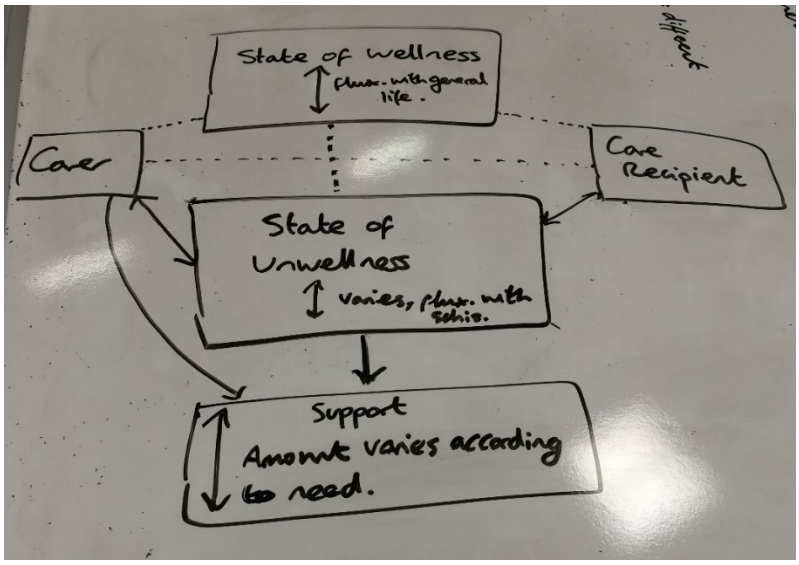
State of unwellness - when CR gets unwell.
this can have a direct effect on carer which
in turn affects their health, which then
affects the CR.

diagnosis CR accesses supp

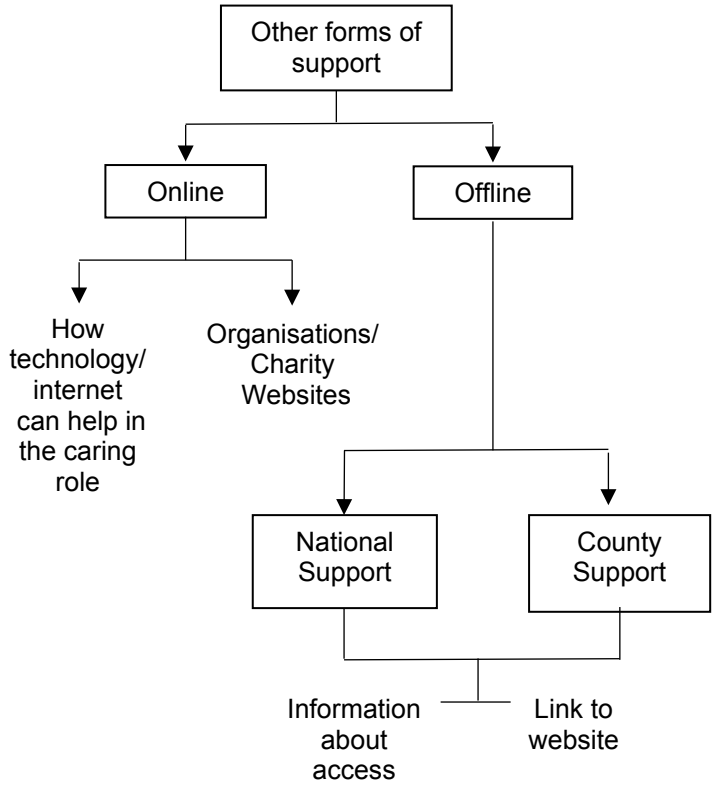
State of unwellness - when CR gets unwell.
this can have a direct effect on carer which
in turn affects their health, which then
affects the CR.

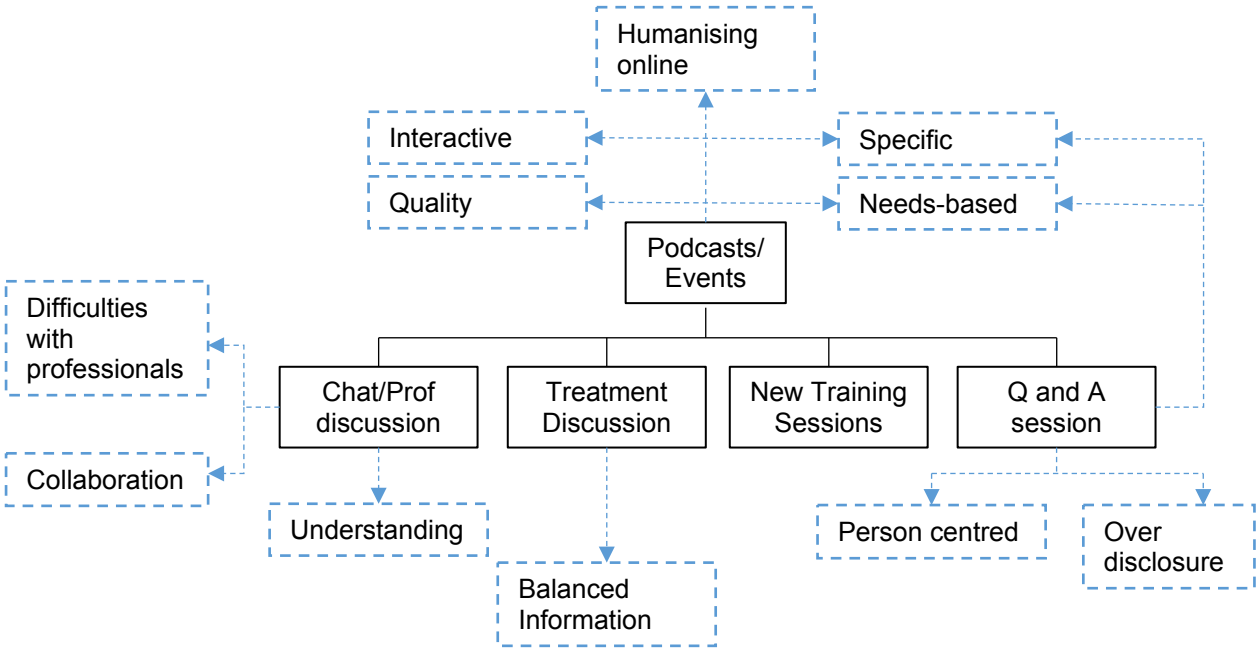
Following diagnosis CR accesses support
which can return them to 'wellness' which
can then affect carer. The carer also has the
chance to access support at this time, inc
chance of returning to 'wellness'

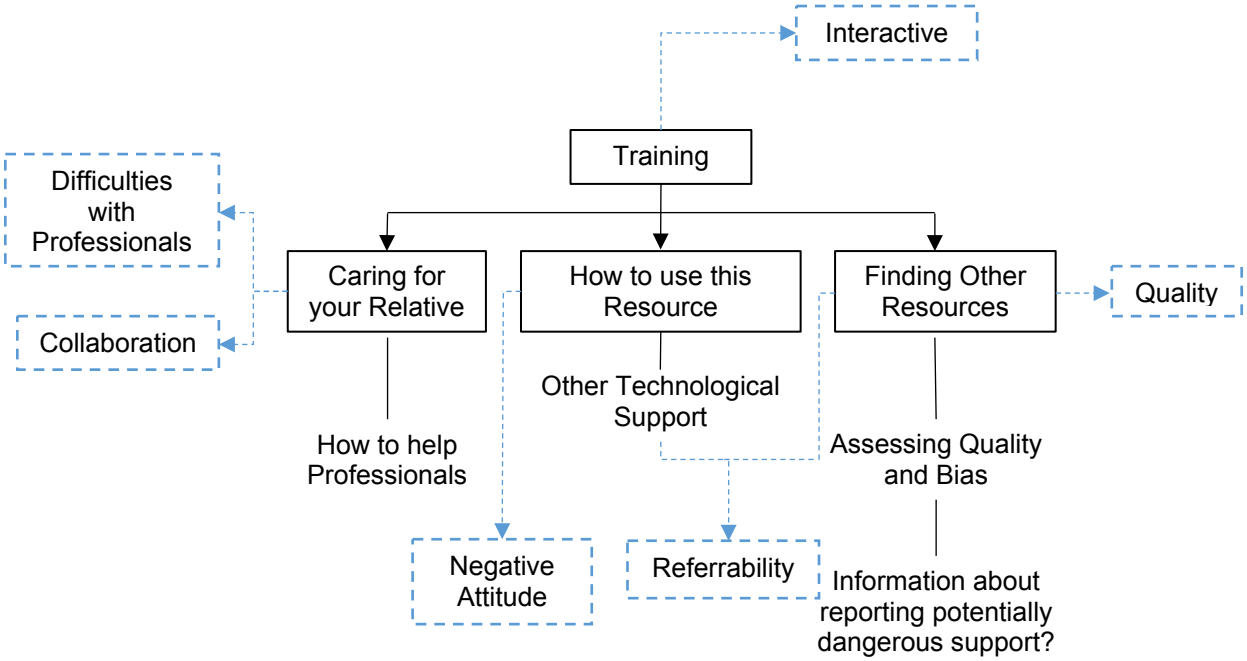

Carer
CR
Wellness


State of Wellness
Carer
Care Recipient
State of Unwellness
Support
Amount varies according to need.

Development of framework for the construction and evaluation of a web-based intervention






Interactive
Training
Difficulties with Professionals
Collaboration
Caring for your Relative
How to use this Resource
Finding Other Resources
Quality
How to help Professionals
Other Technological Support
Assessing Quality and Bias
Negative Attitude
Referrability
Information about reporting potentially dangerous support?

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